

# **PSYCHOSOCIAL FACTORS THAT INFLUENCE SIBLING DONORS DURING ALLOGENEIC BONE MARROW TRANSPLANTATION**

By

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Research Assignment presented in partial fulfilment of the requirements  
for the degree of Masters of Nursing Science at Stellenbosch University



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March 2013

## DECLARATION

I Lena Mc Kenzie hereby certify: The content of this academic paper is my own original work. I have properly acknowledged all sources which I have used in my text references. I am aware by handing in a paper that is not my own original work I may be subjected to disciplinary action.

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## ABSTRACT

Haematopoietic stem cell transplantation has become an increasingly popular treatment option for persons with life-threatening blood related diseases such as leukemia, lymphoma, myeloma and certain forms of anaemia. Due to this new therapy the use of bone marrow from a healthy individual also called a living donor for transplantation is inevitable. These living donors can experience psychological and economic issues and these components needs to be addressed in the transplant protocol. The researcher described the psychosocial factors that influenced sibling donors during allogeneic bone marrow transplantation at a public sector hospital in Cape Town, whether the transplant team members explained the administrative process of the transplant in an understandable manner and language and the effect of the psychosocial factors and administrative process of the allogeneic bone marrow transplantation on the sibling donors.

A quantitative research approach with a descriptive design was used in this study. The sample was selected by means of full population sampling. The final sample size of (n=64) stem cell sibling donors over 18 years of age participated in the study. A self-reporting questionnaire was used to gather data, inclusive of four open-ended questions to establish an in depth sense of what the donor experiences during the bone marrow donation process. Descriptive statistics used to describe the variables included frequency distributions in the form of histograms and frequency tables. The Pearson chi-square statistical analysis test was used to test for relationships amongst groups.

The study drew on the Roy Adaptation Model (RAM) as the theoretical framework to explain the phenomena surrounding the psychosocial and administrative effect of the transplantation process on the sibling donor. Based on the findings the haematopoietic stem cell donors coped with the psychosocial impact of the donation process by making use of their coping mechanism to adapt to their situation according to the Roy Adaptation Model. This model also offers guidance to the nurses to apply this model in nursing practice.

Results revealed that sibling donors developed feelings of anxiety in relation to the invasive procedures that cause them to experience physical pain. Most respondents claimed that they were not psychologically affected by the donation process. The moral obligation the sibling donor has towards his sister or brother outweighed the physical pain or discomfort experienced during the donation process. Results revealed that the

responding donors claimed they were well informed regarding the donation process and understood the treatment plan of the recipient. However, results revealed that there was a lack in visual donor information such as books, pamphlets as well as internet information. Results concerning the demographics revealed that (n=29) respondents had no schooling and some respondents had some schooling which can give an indication of how to bridge the knowledge and information gap between them and the donor in terms of language.

Statistical significance results regarding the emotional state and economic situation of the donors was found. Some of the respondents were responsible for their own transport and their own accommodation, some of those that are employed were responsible for leave without pay. An organ donation policy needs to be developed to prevent live organ donors from losing valuable working hours that could result in loss of salary and should provide other financial incentives. Furthermore, a lack in a post-donation follow-up medical to alleviate and detect post-donation complications was identified.

Further nursing research can help nurses to understand living donation for transplantation, also how the nurses that practice in organ transplant units experience and deal with the psychosocial factors that influence them particularly.

## OPSOMMING

Hematopoïetiese stamseloorplanting het 'n toenemend gewilde-behandelingsopsie vir persone met lewensgevaarlike bloedverwante siektes soos leukemie, limfoom, miëlloom en sekere soorte anemie geword. Vir hierdie tipe terapie word die beenmurg van 'n gesonde individu, ook bekend as 'n lewende skenker, vir oorplanting gebruik. Lewende skenkers kan sielkundige en ekonomiese probleme ervaar en hierdie kwessies moet in die oorplantingsprotokol hanteer word. In hierdie studie is ondersoek ingestel na die psigososiale faktore wat bloedverwante skenkers tydens allogeneïese beenmurgoorplanting by 'n openbare hospitaal in Kaapstad beïnvloed, of die oorplantingspan die administratiewe proses van die oorplanting op 'n verstaanbare manier en in verstaanbare taal verduidelik het, en wat die uitwerking wat die psigososiale faktore en administratiewe proses is op die bloedverwante skenkers tydens allogeneïese beenmurgoorplanting.

'n Kwantitatiewe benadering met 'n beskrywende navorsingsontwerp is in hierdie studie gebruik. Die steekproef is op grond van volledige populasiesteekproefneming gekies. 'n Finale steekproefgrootte van stamselskenkers ( $n=64$ ) ouer as 18 jaar het aan die navorsing deelgeneem. 'n Selfverslaggewende vraelys is gebruik om data in te samel, wat vier oop vrae ingesluit het om grondige begrip te verkry van wat die skenker tydens die beenmurgskenkingsproses ervaar. Beskrywende statistiek wat gebruik is om die veranderlikes te beskryf, sluit in frekwensie-verspreidings in die vorm van histogramme en frekwensie-tabelle. Die Pearson chi-kwadraat- statistieseanalise is gebruik om die verwantskappe onder groepe te toets.

Die Roy Adaptation Model (RAM) is as die teoretiese raamwerk vir die studie gebruik om die verskynsels betrokke by die psigososiale en administratiewe ervaring van die oorplantingsproses vir die bloedverwante skenker te verklaar. Op grond van die bevindinge het die hematopoïetiese stamselskenkers die psigososiale impak van die skenkingsproses hanteer deur gebruik te maak van hulle hanteringsmeganisme om by hulle situasie aan te pas, wat met die RAM ooreenstem. Hierdie model bied ook leiding aan verpleegkundiges om dit in die verplegingspraktyk toe te pas.

Resultate het getoon dat bloedverwante skenkers gevoelens van angs ontwikkel het vanweë die indringende prosedures, wat fisiese pyn veroorsaak het. Die meeste deelnemers het aangedui dat hulle nie sielkundig deur die skenkingsproses geraak is nie. Die morele verpligting wat die bloedverwante skenker het teenoor sy of haar broer of

suster het die fisiese pyn of ongemak gedurende die skenkingsproses oortref. Resultate het getoon dat die deelnemende skenkers aangedui het dat hulle goed ingelig was oor die skenkingsproses en die behandelingsplan van die ontvanger verstaan het. Die resultate dui egter daarop dat daar 'n gebrek was aan visuele skenkersinligting soos boeke, pamflette en internet-inligting. Resultate rakende die demografie het bewys dat van die deelnemers (n=29) ongeskoold en sommige deelnemers laag geskoold is, wat 'n aanduiding kan gee van hoe die kennis- en inligtingsgaping tussen hulle en die skenker ten opsigte van taal oorbrug kan word.

Statisties beduidende resultate rakende die emosionele toestand en ekonomiese situasie van die skenkers is gevind. Sommige deelnemers was verantwoordelik vir hulle eie vervoer en verblyf. Diegene wat werk, het verlof sonder betaling geneem. 'n Orgaanskenkingsbeleid moet ontwikkel word om te verhoed dat lewende orgaanskenkers kosbare werksure verloor, wat kan lei tot 'n verlies aan salaris. Ander finansiële aansporings behoort ook gegee te word. Voorts is 'n gebrek aan opvolg mediese behandeling vir skenkers om skenkingskomplikasies vas te stel en te verlig, geïdentifiseer.

Voortgesette navorsing kan verpleegkundiges help om begrip te verkry van die implikasies van lewende orgaanskenking. Verpleegkundiges wat in hierdie orgaanoorplantings-eenhede werksaam is, kan 'n beter begrip kry van die psigososiale faktore wat hierdie skenkers spesifiek beïnvloed.

## ACKNOWLEDGEMENT

I hereby acknowledge and express my sincere appreciation to:

- The Lord Jesus Christ who gave me the strength to persevere so that I can complete this research project in the prescribed time.
- The sibling stem cell donors who have helped me to understand what they experienced when donating their stem cells to their sibling and what they experienced months and years afterwards.
- To the lecturers and administrative staff of the nursing faculty, as well as the statisticians at the University of Stellenbosch for their professional support and guidance during my academic development.
- My academic supervisor Ms L. Paterson who enriched my professional life.
- My son Lloyd Arthur and daughter Jessica Mc Kenzie for their patience, understanding and encouragement to live my dreams.
- My family members and church congregation for their prayers and words of encouragement.
- My colleagues for their support and motivation to complete this immeasurable task.
- The Groote Schuur Hospital Region Nurses Education Trust (RNET) and UCT Haematology Research Fund for the financial assistance given to fund this research project partially.

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# CHAPTER 1:

## SCIENTIFIC FOUNDATION OF THE STUDY

### 1.1 INTRODUCTION

Haematopoietic stem cell transplantation (HSCT) has become an increasingly popular treatment option for persons with life-threatening blood related diseases, for example acute and chronic leukemia, lymphoma, myeloma, certain forms of anaemia such as aplastic anaemia and other blood-related diseases for whom other forms of therapy have been ineffective.

Cancer is widely viewed as a disease of genetic origin caused by mutations of deoxyribonucleic acid (DNA) that make a cell multiply uncontrollably (Bower & Waxman, 2006:3). Watson, Barrett, Spence and Twelves (2006:134) report that haematological malignancies such as leukemia, lymphoma, myeloma, myelodysplastic syndrome (MDS) and myeloproliferative disorder are the most common causes of cancer in the working population. Langhorne, Fulton and Otto (2007:233-388) define leukemia as a lethal haematological confusion characterized by a proliferation of peculiar white blood cells that infiltrate the bone marrow, peripheral blood, the reticuloendothelial system, lymphatic system, sometimes the central nervous system and organs such as the spleen, liver, ovaries, mouth, heart and lungs. They also state that haematopoietic stem cells are found in the bone marrow which is the spongy tissue found in the inner cavities of bone and in the peripheral blood. Stem cells eventually proliferate into mature erythrocytes (red blood cell), leukocytes (white cell) and platelets. Each kind of mature cell performs a specific function; the red blood cells transport oxygen, the granulocytes is the body's inflammation response also called phagocytosis and the platelets is the clotting factor of the blood (Langhorne *et al.*, 2007:233-388).

Lipton (2003) as cited in Wiener, Steffen-Smith, Fry and Wayne (2007:1) states that over the years scientists developed enough understanding of haematopoietic stem cells to successfully use them as a therapy. This therapy is known as Haematopoietic stem cell transplantation (HSCT) and is now considered a first-line therapy for many life-threatening haematological and oncological diseases. Due to this new therapy the use of bone marrow from a healthy individual also called a living donor for transplantation is inevitable. Living donors can experience psychosocial issues which need to be addressed in the transplant protocol. Allogeneic stem cell transplantation is a transplant in which the patient receives someone else's bone marrow or stem cells. The donor can be related to the

patient, usually a sibling or unrelated donor with no relation to the patient (Langhorne *et al.*, 2007:233-388). Allogeneic stem cell transplantation is also a very aggressive and demanding medical therapy with unpredictable outcomes that presents both psychological and physical challenges. Studies examining psychological functioning in sibling donors are primarily limited to bone marrow transplant donors (Wiener, Steffen-Smith, Battles, Wayne, Love & Fry, 2008:304).

The South African Stem Cell Transplantation Society (SASCeTS:31) reports that haematopoietic stem cell transplantation (HSCT) is a widely used therapy of which an estimated 45-50 000 HSCTs are carried out annually worldwide. An increasing proportion of donors are now mostly unrelated volunteers. In 2005, 41% of allogeneic stem cell transplants were reported to a non-profit organisation the European Group for Blood and Marrow Transplantation (EBMT) based in Maastricht, The Netherlands. This group used unrelated donors, of who about 70% donated peripheral blood stem cells (Pamphilon, Siddiq, Brunskill, Doree, Hyde, Horowitz & Stanworth, 2009:71). The South African Bone Marrow Registry (SABMR) is now accepted as a full participant in the world-wide programme, having provided donors to local patients, as well as to international patients as reported (SASCeTS:31).

In South Africa there are more blood disorder treatment centres, both in the public and private health sector in relation to a few bone marrow transplantation units. Haematopoietic stem cell transplantation (HSCT) became a common procedure at university hospitals in Johannesburg and in Cape Town in the mid-1980s. Although initially most transplants were autologous, there has been a substantial growth in allogeneic transplantation since the early 1990s, particularly in Cape Town (SASCeTS:31). An autologous transplant is a transplant in which the patient's own bone marrow or stem cells are collected, placed in frozen storage and reinfused into the patient later (Langhorne *et al.*, 2007:233-388).

Groote Schuur Hospital's Haematology Department in Cape Town serves and treats patients in the public health sector from the Western Cape and all other provinces in the country, as well as patients referred from the military hospital. Groote Schuur Hospital is renowned for its fully fledged bone marrow transplantation programme in the public health sector in South Africa. This unit does haematopoietic stem cell transplants on children and adults from its own unit, as well as patient referrals from other treatment centres, making use of paediatric, adolescents and adults donors, and does allogeneic and autologous transplants, transplants on patients with leukemia, aplastic anaemia and other haematological malignancies such as lymphoma. At Groote Schuur Hospital 25 to 30



peripheral blood stem cell transplants from a mixture of blood related diseases are done per year. There are several private transplant units in the private health sector, based in Cape Town, Johannesburg, Pretoria and in Bloemfontein. More allogeneic haematopoietic stem cell transplants from matched unrelated volunteer donors and matched related sibling donors are done in the private sector per year due to availability of funds and resources (SASCeTS:31).

In the public health sector sibling allogeneic and autologous transplantations are the choice of treatment. It is cost effective to first focus on the siblings to select a compatible human leukocyte antigen (HLA) donor due to financial constraints. It is also preferable to search for a donor amongst siblings, because the chances are good in finding a compatible donor. Wiener *et al.* (2008:304) found that siblings are most often selected as donors since they have the greatest chance (25%) of being HLA-matched with the recipient. Human leukocyte antigen typing (HLA-typing) is a laboratory assessment technique used to select an immunologically compatible donor.

In this thesis the researcher will at times refer to bone marrow as stem cells. The actual process that takes place is haematopoietic stem cells donation as the therapeutic intervention.

## **1.2 DEFINITION TERMS**

### **1.2.1 Allogeneic transplant**

This is a transplant in which the patient receives someone else's bone marrow or stem cells. There are several types of allogeneic transplants, with each type named according to the donor: syngeneic - the donor is the patient's identical twin; related – the donor is related to the recipient, usually a sibling; unrelated – the donor is of no relation to the recipient (Langhorne *et al.*, 2007:388).

### **1.2.2 Psychosocial factors**

These refer to the many phases of the cancer course that the cancer patient and the family have to adjust to, such as the diagnosis, treatment, after treatment, long term survival and completion of life (Langhorne *et al.*, 2007:524).

### **1.2.3 Transplantation process**

Haematopoietic stem cell transplantation (HSCT) is the process of replacing diseased or damaged bone marrow with normally functioning bone marrow. The bone marrow can be

the patient's own bone marrow or stem cells or the patient receives someone else's bone marrow or stem cells (Langhorne *et al.*, 2007:388).

### 1.3 RATIONALE FOR THE STUDY

When a patient is positively diagnosed with leukemia or another life-threatening blood disease the siblings of this patient are called to get tested to find a compatible blood cell donor. These tests need to be done in order to try and save the patient's life and not to waste unnecessary time. The time factor is of such crucial importance because the time from diagnosis needs to be taken into consideration. The siblings will come to the hospital where the necessary tests are performed and once the HLA test has established the compatibility, the donor has to go through a range of procedures. It is at this point where the possible sibling donor's psychosocial issues or concerns come to the fore. Siblings ask questions regarding the donation procedure, the treatment of the patient and the success rate of the transplant. Siblings who are in the workforce clearly show signs of nervousness and or agitation which might be due to time taken off from work without pay. Packman (1999:701) claimed that investigators had earlier noted that sibling donors may be at risk for behavioural problems and anxiety, while nondonors may experience ambivalent feelings of disappointment and relief. It was suggested that psychosocial stages of bone marrow transplantation (BMT) may parallel the medical transplant process, with high levels of stress experienced, namely pre-BMT, during hospitalization and post discharge.

Furthermore, the healthy person has to undergo invasive procedures without being given a reasonable amount of time to comprehend this duty or responsibility to save a person's life. The donor is required to go through a blood test to exclude infections that can be transmitted through the stem cells. This can put the patient at risk to be infected with the Hepatitis B virus (HBV), the Hepatitis C virus (HCV) and Human immunodeficiency virus (HIV) according to Horowitz and Confer (2005:469) to assess the donor for risks to the patient. These tests will identify the donor's behaviour associated with transmissible diseases and can expose the donor's lifestyle and his/her right to privacy.

The donor has the responsibility to have a bone marrow biopsy under local anaesthetic to exclude any possibility of bone marrow disease or pathology. This part of the donation process is associated with great fear, anxiety and pain. In addition, the donor has a responsibility to inject him/herself subcutaneously and the suitable places are the back of the arms, top of the thighs, and the abdomen except for the umbilical area. When teaching the donor or other relative to administer the injection at home fear or anxiety is

shown. Fortanier, Kuentz, Sutton, Milpied, Michalet, Macquart-Moulin, Faucher, Le Corroller, Moatti and Blaise (2002:148) confirmed that G-CSF stimulation is the most painful part of the harvesting procedure for blood cell donors. The pain is in the form of headaches and bone pain, but it can be treated with a mild analgesia with effect. It is preferable for the donor to experience bone pain or backache following G-CSF stimulation due to the dramatic increase in white blood cells, than to have bone marrow collected by needle aspiration from the hip bone, sternum or vertebra and experience serious psychological reactions.

Neupogen or Filgrastim, granulocyte colony-stimulating factor (G-CSF) should be given for 5 to 6 days to mobilise the haematopoietic progenitor cells into the peripheral blood. The use of haematopoietic growth factors has made it possible to collect haematopoietic precursors from peripheral blood which is required for the transplantation process (Munzenbreger, Fortanier, Macquart-Moulin, Faucher, Novakovitch, Maraninchi, Moatti, & Blaise, 1999:55). These haematopoietic progenitor cells or also known as undifferentiated cells are collected for the purpose to infuse into the patient. The donor is once again subjected to another invasive procedure, the insertion of an intravenous femoral catheter under local anaesthetic to provide venous access to collect the haematopoietic stem cells. The donor can suffer adverse effects such as the veins which can bruise, lead to a haematoma or cause minor bleeding. This peripheral blood stem cell collection procedure can be a few hours to two days to collect an adequate amount of undifferentiated cells according to the transplantation protocol.

Finally, the procedure in the collection of peripheral blood stem cells requires one to two days apheresis where the donor's blood is processed using a cell separator machine. The healthy individual experiences inconveniences like being confined to a bed for hours during the collection period and has to rely totally on the nursing and medical staff to supply her / his needs.

Allogeneic peripheral blood stem cells (PBSC) donation, involves the administration of G-CSF. The captured PBSCs from the donor are administered to the patient and may engraft more quickly than stem cells collected from bone marrow and yield a shorter patient recovery time (Switzer, Goycoolea, Dew, Graeff & Hegland, 2001:917).

All of these procedures happen in an outpatient setting with regular day visits from the sibling donor. Donors have to stay away from work without pay, have to travel from afar on their own expense and have to leave their families and homes for days. The donor gives informed consent to the medical officer to donate haematopoietic stem cells through

the procedures such as blood tests for infectious diseases, bone marrow biopsy, the insertion of the intravenous femoral catheter and the peripheral stem cell collection via the cell separator.

Routine donor follow-up after the donation process needs to be highlighted, because it can be ignored. It was found that proper follow-up after the donation is vital to donors since they need reassurance because of the uncertainty surrounding the human growth factor injection (Munzenberger *et al.* 1999:61). Halter, Koderer, Ispizua, Greinix, Schmitz, Favre, Baldomero, Niederwieser, Apperley and Gratwohl (2009:99) confirm that there is a lack of a donor follow-up system to capture the adverse effects of the transplantation process in terms of the donor in some bone marrow transplant centres.

Donors reported that they experience physical symptoms and or side-effects, such as bone pain, lower back pain, headaches, fatigue, nausea/vomiting, problems sleeping, fever, needle site pain, pain and swelling at groins (Switzer *et al.*, 2001:919). Chang, McGarigle, Koby, Joseph and Antin (2003:63) reported that the relationship to the recipient does not protect the related donor from the pain experienced after donation of either marrow or peripheral blood stem cells. Just as the transplant recipients have a programme of scheduled pre- and post-transplant appointments, related donors may benefit from a similar course with professionals who are able to evaluate them for adverse physical and psychological reactions. Moreover, the related or unrelated donors are the other transplant patients. An earlier study by Kinrade (1987) cited in Wiener *et al.* (2007:2) stated that younger siblings can find the human leukocyte antigen blood typing frightening and painful and would therefore wish not to donate. Paediatric sibling donors manifested difficulty in adjusting to the role as donor. The parents reported that the sibling had sleep difficulties, refused to talk about being a donor, talked excessively about the pain expected and had problems in school.

It was found that unrelated donors have been the focus of more studies, because of the widespread assumption that family members are naturally motivated by the prospect of saving a loved one. What was also found is that the inconvenience generated by the harvesting procedure was subjectively limited in the donor's experience, suggesting that the symbolic dimension of gift and familial solidarity involved in allogeneic transplantation partly compensate for the pain, discomfort and psychological stress which is generated by the technical medical procedures that donors have to undergo (Chang *et al.*, 2003:59); (Fortanier *et al.*, 2002:148).

Also risk factors for poor psychological functioning include age at donation, recipient death and transplant complications such as graft-versus-host disease (GVHD). Langhorne *et al.* (2007:233-396) state that GVHD is a complication that can occur after allogeneic transplant. It is an immune-related reaction of the newly grafted stem cells to the body of the recipient and involves the skin, the gastrointestinal tract and the liver. The skin is characterised by a rash and the gastrointestinal tract involvement is characterised by nausea, vomiting and diarrhoea and the liver is characterised by jaundice, elevated liver function and an enlarged liver.

Health professionals should be aware that merely raising the issue of live organ donation may instigate powerful psychosocial processes such as fear, anxiety, pain and financial loss. These processes can influence the potential donor's voluntary control and leave little room to refuse and the individual can become blameful. The obligation to donate can be overridden such as one's responsibility to the spouse, children or to oneself, because of the risk of death that is small, but real. The donor must not feel threatened or experience undue pressure to donate, therefore consent to donate has to be voluntary and informed. A journal about kidney donors reflects that it is imperative that every potential living donor undergoes a comprehensive psychosocial evaluation by a professional person such as a social worker, psychologist or psychiatrist who is knowledgeable about kidney transplantation and living donation. The essential components of the psychosocial evaluation should include an assessment of competency, knowledge and understanding of donation risks and benefits (Rodrigue, Pavlakis, Danovitch, Johnson, Karp, Khwaja, Hanto & Mandelbrot, 2007:2330).

## 1.4 LITERATURE REVIEW

Most literature that could be found focused more on the unrelated donor's psychosocial experience due to bone marrow transplant than the related or sibling donors. Wiener *et al.* (2008:307) found that siblings make up the largest percentage of matched donors for allogeneic transplant procedures, yet little information is obtainable on the psychological effect of stem cell donation. Related donors will not only live through the procedural risks related to marrow donation, but also many of the psychological and emotional sufferings experienced by the transplant patient (Chang *et al.*, 2003:59-60). Donors related to the recipient have a personal interest in the transplant outcome, and it is possible that they might minimise the effect the donation procedure had on their quality of life (Pamphilon *et al.*, 2009:73). Wiener *et al.* (2007:6) state that donors from successful transplants often report that their family is closer, relationship with the ill sibling has improved and have insight into the recipient's illness. However, donors from unsuccessful transplants respond

to the transplant process with anger, guilt and blame when the recipient becomes ill, rejects the graft or die.

Wiener *et al.* (2008:304) reported that allogeneic stem cell transplantations lead to both psychological and physical difficulties and found that the psychological experiences the donor could endure during the transplantation process are such as withdrawal, depression, behavioural problems, low self-esteem, identity problems, anger, guilt and blame. They also reported that success or failure of the transplant can affect the donor positively, such as improved family relationships, cohesion and a decrease in feelings of helplessness, but may give rise to negative feelings, such as anger, guilt and blame.

Pentz, Haight, Noll, Barfield, Pelletier, Davies, Alderfer and Hinds (2008:149) reported that more attention can be paid to the donor's needs, such as a design of a follow-up system. Halter, Koderer, Ispizua, Greinix, Schmitz, Favre, Baldomero, Niederwieser, Apperley and Gratwohl (2009:96-100), noted that certain bone marrow transplant teams are having active follow-up systems, but should be extended to donors as well which should be of great importance. Of great importance is the fact that few studies describe the adverse events after the stem cell donation related to the haematopoietic growth factors Neupogen or Filgrastim, granulocyte colony-stimulating factor (G-CSF), such as headaches, nausea, vomiting, fatigue and an injection site reaction (Horowitz & Confer, 2005:472). Another adverse event is death and by having these follow-up systems aspects as these could be duly noted.

Halter *et al.* (2009:100) stated that donors must be informed about the potential risks of the donation procedure. Even for healthy related or unrelated donors the donation procedure is not without risk of disease or, rarely, death. Pamphilon *et al.* (2009:72) found that both physical and psychological side-effects were reported from the haematopoietic stem cell collection. Halter *et al.* (2009:95-100) reported that stem cell harvesting in healthy donors has been viewed absolutely safe, but fatal events are reported amongst related donors. Infrequent reports of severe or even life-threatening adverse events such as death, vascular events, bleeding, rupture of the spleen and the triggering of inflammatory disease, as well as haematologic malignancies were reported. Bone marrow harvest centres need to know about potential complications and need to inform donors about their risks.

Wiener *et al.* (2008:306) Smith Glasgow and Bellow (2007:370) reported that the transplant team should provide the donor with knowledge of the transplant and that extra

preparation sessions will be valuable. Education of patients and the lay community is entirely the role of nurses in hospitals, communities and other settings.

Wiener *et al.* (2008:306) noted that there is limited educational material on stem cell donation obtainable to children and to teenagers. Ross (2010:733-735) noted that to reduce the donor being forced to donate to families he/she must be educated and must have adequate information about living donation before the human leukocyte antigen (HLA) typing blood test so that they can have time to reflect and make a fully informed decision. Information to possible donors regarding the entire donation process should be given early and the communication channel between the donor and the transplant team must be open and transparent. Wiener *et al.* (2007:7-9) identified that younger sibling donors often express feelings of “no choice” in becoming a donor, because the parents give consent. In addition, they supported previous researchers’ view that education about the haematopoietic stem cell transplantation (HSCT) process alone is inadequate and that children or minors should receive information beforehand and have chances to express concerns and questions in order to manage anxiety and guilt. Some approaches include a tour of the hospital and getting introduced to the transplant team so that donors can familiarise themselves with the hospital environment. Wilkins and Woodgate (2007:E31) noted that siblings also focus on the positive outcome of the transplant which includes the understanding of the illness, more family cohesion, obtaining better grades at school and fewer arguments amongst siblings.

## **1.5 PROBLEM STATEMENT**

Living donors who donate haematopoietic stem cells to patients with life-threatening haematologic and oncologic diseases that have no Medical Aid or Medical Insurance experience psychological and economic issues in a third world or developing country. Sibling donors for allogeneic bone marrow transplantation are not well informed regarding the treatment of the patient and the standard of the donation process. There is a gap in knowledge from the donors what the bone marrow donation process entails and it needs to be filled.

## **1.6 SIGNIFICANCE OF THE STUDY**

The researcher wants to make the government and service provider aware of the issues related to stem cell donation and proposes to come up with an awareness and follow-up plan for donors in order to make the entire donation process less stressful.



## **1.7 RESEARCH QUESTION**

What psychosocial and administrative factors influence sibling donors during allogeneic bone marrow transplantation and the effect thereof on sibling donors?

## **1.8 RESEARCH PURPOSE AND OBJECTIVES**

The purpose of the study is to describe the psychosocial factors that influence sibling donors during allogeneic bone marrow transplantation. The specific objectives of the study are to describe:

- the psychosocial factors that influence sibling donors during allogeneic bone marrow transplantation at a public sector hospital in Cape Town.
- whether the transplant team members provided and explained the administrative process of the transplant in an understandable manner and language.
- the effect of the psychosocial factors and administrative process of the allogeneic bone marrow transplantation on the sibling donors.

## **1.9 RESEARCH METHODOLOGY**

### **1.9.1 Research design**

A research design is an overall plan to answer the research question. It is also stated that it is a plan or blueprint of how you intend conducting the research. It maximises the researcher's control over the factors that could interfere with the validity of the findings and therefore guides in planning and implementing the study in a way that is most likely to achieve the intended goal. The researcher uses the problem statement, framework, research question and defined variables to map out the design to achieve a detailed plan for collecting and analysing data (Burns & Grove, 2009:218-219; Mouton, 2001:55).

This study will use a quantitative research approach with a descriptive design, whereby the researcher will use a Likert scale with closed ended questions and with four open-ended questions which will be analysed qualitatively. A quantitative, rather than a qualitative study should be employed due to the possible demographic positioning, financial liability and any unresolved emotional impact the donation process might have had on the donor, as well as the family of the donor.



### **1.9.2 Population and sampling**

A population can be composed of people, animals, objects or events that meet certain criteria for inclusion in a given study. Sampling is the process for selecting a group of people, events, behaviours or other elements with which to conduct a study (Burns & Grove, 2009:42; LoBiondo-Wood & Haber, 2010:221). The target population is the entire set of individuals or elements who meet the sampling criteria and an accessible population is the portion of the target population to which the researcher has reasonable access (LoBiondo-Wood & Haber, 2010:222).

In quantitative research the researcher uses both random and non-random sampling methods to obtain study samples. Random sampling methods usually provide a sample that is representative of a population, because each member of the population has a probability greater than zero of being selected for a study (Burns & Grove, 2009:35).

The target population for this study would be the siblings of current and deceased bone marrow transplant patients. The sample will be obtained from the accessible population of the bone marrow donors. No specific type of sampling method will be used, therefore this study will make use of full population sampling. The whole population will be used as the sample is small. Based on past records there are roughly 25 bone marrow transplants performed each year. Of these, approximately 12 per year are sibling donors that will be eligible for inclusion in this study.

The sample will only be obtainable at a single site where the research will be conducted, because it is the only state hospital that runs a fully-fledged bone marrow transplantation programme in the public health sector in South Africa. The researcher will access the database system for contact information that could exceed 10 years (2000-2010).

### **1.9.3 Inclusion and exclusion criteria**

The sample criteria determine the target population which is the sibling donor in this study. The sample will be selected from the accessible population within the target population.

#### *1.9.3.1 Inclusion criteria*

The inclusion criteria for this study are:

- Adults who are over 18 years of age at the time of the study
- Sibling male and female bone marrow donors
- Siblings who are able to comprehend and communicate their understanding of the bone marrow donation process in English and Afrikaans
- Siblings who are residing within South Africa.

#### **1.9.3.2 Exclusion criteria**

The exclusion criteria for this study are:

- Sibling bone marrow donors younger than 18 years
- Prisoners due to accessibility
- Mentally incapacitated donors
- Siblings who live outside the borders of South Africa.

#### **1.9.4 Instrumentation**

Questionnaires are frequently used in descriptive studies to collect a broad spectrum of information from subjects. Like interviews, questionnaires can have a choice of structures such as it can ask open-ended questions which require a written response from the subject or close-ended questions which have only answers chosen by the researcher.

A scale is a measure in which a researcher captures the intensity, direction, level or potency of a variable construct. A Likert-type scale determines the opinion or attitude of a person and contains a number of declarative statements with a scale after each statement. Response choices on a Likert scale usually address agreement, evaluation or frequency as reported in Burns and Grove (2007:384-388).

The research instrument used in this study will be a questionnaire to determine beliefs, attitudes, opinions or intentions of the sibling donors. The questions to the donors will be presented in a consistent manner, therefore there will be less opportunity for bias. Closed-ended, open-ended and yes/no questions will be asked. The survey will use a Likert scale and the questionnaire will be structured according to the objectives that are the psychosocial factors and administrating process of the transplantation that are affecting the sibling bone marrow donors.

A few open-ended questions will be asked to establish sense of what the donor experienced during the bone marrow donation process.

The questionnaire will only be in English and Afrikaans.

##### **1.9.4.1 Validity and Reliability**

It is essential that an instrument be both reliable and valid for measuring a study variable in a population. Therefore, a tool is reliable if it consistently measures what it is supposed to measure and it is considered valid if it accurately measures what it is intended to measure (Burns & Grove, 2009:380-384).

#### **1.9.4.2 Reliability**

This refers to the dependability or consistency when the same thing is repeated or recurs under identical or very similar conditions (Neuman, 2003:178). The reliability of the research will be determined by the statistician prior to and after the completion of the pilot study to ascertain the validity and the reliability of the measurement tool, including the transferability thereof.

#### **1.9.4.3 Validity**

It addresses the question of how well the social reality being measured through research matches with the constructs researchers use to understand it (Neuman, 2003:179).

Validity has two aspects that the instrument actually measures, the concept in question and that the concept is measured accurately (Delpont, 2005:160).

The content of the scale will be examined by a panel of trained nurses in the field of oncology. The panel of experts will examine whether or not the states described in the scales represent states of psychosocial and economic issues. The scale will also be reviewed by the experts for its level of clarity, user-friendliness and speed.

#### **1.9.5 Pilot study**

A pilot study is commonly defined as a smaller version of a proposed study conducted to refine the methodology or to develop various steps in the research process. This pilot study will be conducted to refine and to examine the reliability and validity of the questionnaire. The questionnaire will be pilot-tested to determine the clarity of questions, effectiveness of instructions, completeness of response sets, time required to complete the questionnaire and success of data collection techniques (Burns & Grove, 2009:44).

#### **1.9.6 Data collection**

In quantitative research data collection involves obtaining numerical data to address the research objectives, questions or hypotheses. Data collection is the process of selecting subjects and gathering data from these subjects (Burns & Grove, 2009:43-441).

The researcher will utilize about four to five weeks in order to mail and collect data from the respondents. The researcher will phone the respective respondents informing them of the consent form and the survey that will be posted. For those unable to be contacted by phone, the researcher will send both the informed consent form and the survey to be completed. To raise the response rate the researcher will towards the end of the fourth week make another courtesy call to enquire about the return thereof. The researcher will

ensure anonymity by ensuring that no names are put on the questionnaire and that a self-addressed envelope is included with the mailed consent form and questionnaire. A self-addressed envelope will be included with the mailed questionnaire. These telephone calls will be made on the researcher's expense.

The questionnaire will be mailed to the respondent due to certain advantages it has, such as cost effectiveness, the donor will complete it in her/his own time within the given time frame and information will be obtained from a larger stem cell donation group. Another advantage is that the possibility of harmful influence of the fieldworker or researcher is eliminated. The limitations of the mailed questionnaire is that the non-response rate can be high and that there will be no control to ensure that the donor will complete the questionnaire as reported in Delport (2005:167). The respondents will have a time frame of about four weeks in which to complete the questionnaires. The researcher will collect the questionnaires and keep it in a safe place. Mailed questionnaires will have no personal details on it to ensure anonymity, however if the participant requires counselling the anonymity would be affected in order to ensure further counselling and support.

### **1.9.7 Data analysis and interpretation**

Data analysis means the categorising, ordering, manipulating and summarising of data to obtain answers to the research question. The purpose of analysis is to lessen the data to an interpretable form so that the relations of the research problems can be studied, tested and conclusions drawn (Kruger, De Vos, Fouché & Venter, 2005:218). Investigators base their choice of analysis techniques primarily on the research objectives, questions or hypotheses and the level of measurement achieved by the research instruments (Burns & Grove, 2007:42).

In this study the researcher will use a computer to perform the analysis on an easy to use data analysis package. MS Excel will be used to capture the data and STATISTICA version 9 (StatSoft Inc. 2009), STATISTICA (data analysis software) will be used to analyse the data.

The results will be presented with histograms and or frequency tables. It will explain the significance of the findings, form conclusions, generalise the findings, consider the implications for nursing and suggest further studies.

### **1.9.8 Ethical consideration**

Ethical issues considered in this study included the rights of the respondents, institution and the scientific honesty on the part of the researcher.

#### *1.9.8.1 Rights of the respondents*

The respondents will have the right to privacy, their confidentiality and anonymity will be guaranteed and the confidentiality of data will be protected. Respondents need to give informed consent and should be free to withdraw from the project at any time. The respondents will be given clear information about the project (Neuman, 2003:302; Davies, 2007:45). This researcher will respect the privacy, as well as the culture of the donor.

The consent of the participant will be obtained in writing and will be communicated to each donor prior to the commencement of the research telephonically. The consent will be mailed to the participants and once the participants decide to partake, they should then sign the consent and return it. When and if the donor becomes too emotional when answering certain questions the researcher will ensure that a counsellor is available for debriefing when any unresolved emotions need to be dealt with. A counsellor was available for the respondents in the event of needing counselling. For this reason, the researcher in advanced consulted with the counsellor in the Department in advance who agreed to assist with telephonic counselling at any time.

#### *1.9.8.2 Right of the institution*

The researcher will apply for ethics review and approval to conduct the research from the Health Research Ethics Committees (HREC) of Stellenbosch University, Provincial Department of Health and the Ethics committee of Groote Schuur Hospital. The researcher will obtain hospital authorisation to be able to gather information that was entered in the files of the donors.

#### *1.9.8.3 Scientific honesty of the researcher*

The researcher will at all times strive to maintain objectivity and integrity in the conduct of the research, therefore the data should not be falsified nor manipulated in order to maintain the quality of the research and of the report (Mouton, 2001:240). The period of the data collection will include those donors who have donated up to 10 years ago due to the small sample size.

### **1.9.9 Limitations**

Limitations are restrictions or problems in a study that may lessen the credibility and generalizability of the findings (Burns & Grove, 2007:37). In this study the donors might become too emotional and that might affect their judgement when answering the questions. Due to the small sample size the donors that donated up to 10 years ago may not recall clearly the bone marrow donation experience.

## **1.10 CONCEPTUAL FRAMEWORK**

This study will provide a conceptual framework so that the research question and methodology can be understood better. Lo Biondo-Wood and Haber (2010:57) defined conceptual framework or theoretical framework of a research report as a structure of either concepts or theories pulled together as a map for the study that provides a rationale for the development of the research question or hypothesis. For the purpose of the study the researcher will use the Roy Adaptation Model (RAM) which is a system theory, as the theoretical framework to reflect the study objectives.

## **1.11 ABBREVIATIONS**

Haematopoietic stem cell transplantation (HSCT)

Bone marrow transplantation (BMT)

Human leukocyte antigen (HLA)

South African Stem Cell Transplantation Society (SASCeTS)

Peripheral blood stem cells (PBSC)

Graft-versus-host disease (GVHD).

Granulocyte-colony stimulating factor (G-CSF)

Peripheral blood progenitor cells (PBPC)

Quality of Life (QoL)

## **1.12 SUMMARY**

In this chapter the discussion was about stem cell or bone marrow donation and transplantations that are on the increase. The researcher described the rationale for the study.

## **1.13 CONCLUSION**

In this chapter the literature review, research design and research methodology and conceptual framework were just a brief discussion. The literature review which serves as a support for the rationale and as the conceptual framework will be discussed in chapter two.

## **CHAPTER 2:**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

Nurses need knowledge of psychology to understand the physical, psychological, social and spiritual needs of the client. According to Van Vuren (2006:3) psychology is a scientific study of behaviour and experiences, carried out in a manner that enables us to draw out general principles and to achieve an understanding of the unique nature and quality of an individual's experiences as a human being.

To reflect the study objectives, the researcher will describe the effects of the bone marrow transplantation process on the bone marrow donors whose siblings are either alive or who died.

Gratwohl and Baldomero (2009:423) show that Human Leukocyte Antigen (HLA) – identical peripheral blood stem cell sibling donor aspects have long been neglected by the transplant community. Therefore, there is no established network for collecting a systematic outcome of donors outside the unrelated donor registries. Therefore, this study will draw on diverse approaches of what has been done in the field of psychosocial issues affecting the sibling bone marrow donor during an allogeneic bone marrow transplantation.

Following, the researcher will describe the psychosocial issues and the administration process affecting the sibling bone marrow donor during an allogeneic bone marrow transplantation and the effects thereof. Emphasis has been placed on the Haematology and Oncology (bone marrow) outpatient clinic and wards for the sole purpose of this research assignment.

#### **2.2 DONOR AND LIVING DONATION**

Hader (2006:31-32) reported that live organ donations have outpaced cadaver donations in the past several years. A consensus statement from experts in organ donation believe that a live organ donor should be competent, willing to donate, free from coercion, medically and psychosocially suitable, fully informed of the risks and benefits as a donor and fully informed of the risks, benefits and alternative treatment available to the recipient. The benefits to both donor and recipient must outweigh the risks associated with the donation and transplantation of the living donor organ. According to Pera and Van Tonder (2011:148-156) patients are at the centre of all health services and healthcare, therefore

the rights of patients are the most important moral issues nurses have to deal with. The human rights in the health care context are:

- that any person has a right to treatment and a right to refuse treatment
- the right to information about available health services to information about diagnosis and prognosis
- the right to confidentiality and privacy
- the right of a person to self-determination.

The use of live organ donors is considerably less expensive because of relatively short hospital lengths of stay and rapid improvement in the health status of the recipient.

As donors for an allogeneic stem cell transplant require an exact Human Leukocyte Antigen match with the recipient, most patients requiring transplantation do not have a readily available donor. Siblings are the usual source of donors being the only readily available matched family members. With the smaller families today, only about 10% of patients will have an HLA matched sibling donor. In addition, there is a growth of the role of allogeneic stem cell transplantation in malignant and non-malignant haematological disease which can result in finding an alternative source of donors. This alternative source of stem cells is a matched unrelated donor (MUD) transplant.

The limitation is that the South African Bone Marrow Registry (SABMR) has a lack of funds to do tissue typing and there is also a lack of matched unrelated donor awareness on their part. An additional problem is that there is a lack of black donors in South Africa that makes MUD transplantation a major problem. Literature identified that the United States of America (USA) have a very ethnically diverse population, but the high cost and strict regulations of the National Marrow Donor Program (NMDP) limit international access to USA donors (Ruff, Schlaphoff & du Toit, 2006:6-8).

The current limitation of bone marrow transplantation results from a shortage of suitable HLA-matched donors and complications associated with HLA-disparities. In the absence of a suitable HLA identical sibling donor or a matched unrelated donor, mismatched donors are often used. However, an increased risk of morbidity and mortality exist with the alternative, despite current clinical trials to improve the success of mismatched transplants (Smith Glasgow & Bello, 2007:370).

Donating marrow may seem like a small risk relative to the issues facing the recipients of this marrow, but donors should not be ignored. The risky nature of the transplant for the recipient should in fact increase our interest and concern for the welfare of the donor. If



the donor's experience is negative, it is difficult to promote such a risky procedure as bone marrow transplantation (Whedon, 1991:356).

## **2.3 DONOR CARE**

Antin and Yolin Raley (2009:16) reported that in terms of pretransplant counselling both patient and donor must be completely evaluated before stem cell transplantation. Both patient and donor evaluations should include a thorough history, a physical examination and a series of studies to confirm medical eligibility. Treatment recommendations should be discussed thoroughly with the patient, donor and family. The marrow graft procedure, as well as alternative forms of therapy should be presented as objectively as possible. The risks and hazards of stem cell mobilization and the donation procedures associated with the donation must be explained to the donor, as well as the patient.

The recommended workup for the donor is a complete physical examination, blood workup and infectious disease testing. Furthermore, donor education is to provide the donor with reading material, also with education not to ingest bone marrow suppressive agents for this period, mobilization therapy, administrative information with doctors and nurses and on request, to provide an impartial donor advocate available. If necessary a donor appointment such as consultation and informed consent sessions with the transplant doctor, social worker or a psychosocial consult before donation should be made (Antin & Yolin Raley, 2009:20-21).

Halter *et al.* (2009:95-99) state that haematopoietic stem cell donation is considered a relatively safe procedure for the donor and that adverse events before, during and after donation are frequent but most of them are transient, self-limited and without long-term consequences, nevertheless donors must be informed about the potential risks of making a donation. Furthermore, Gratwohl and Baldomero (2009:423) reported that no systematic donor follow-up exists for sibling donors and that severe donor events are rare, but they can occur.

### **2.3.1 Psychological care**

Van Vuren (2006:103-107) reported that human emotions are highly complex experiences of arousal that are associated with physical activation that can direct behaviour and have a subjective impact. There are proposed basic emotions such as acceptance, anger, anticipation, disgust, fear, joy, sadness and surprise which could be experienced. These emotions can be combined to form more complex ones such as love (joy + acceptance) and remorse (disgust + sadness).

In practice the researcher observed that the siblings that are identified to be the stem cell donors clearly showed signs of nervousness and asked questions such as whether the procedures such as the bone marrow biopsy and the stem cell collection is painful or whether it is the right thing they are doing and whether it will save their brother or sister's life. Anxiety is an emotion aroused by actual or symbolic threat of danger. It gives a person feelings of uneasiness and apprehension, it is accompanied by psychological changes in the body which give rise to symptoms such as dry mouth, nausea, raised blood pressure, palpitations, frequency of micturition, diarrhea, muscle tension, increased pulse and respiratory rates (Martin, 1995:283). According to Fortanier *et al.* (2002:148), levels of anxiety before the collection procedure in their study were fairly high in both blood cell and bone marrow groups of donors. According to De Oliveira-Cardoso, Santos, Mastropietro and Voltarelli (2010:913), the donor's motive is identified potentially as the saviour of the life of a family member which is difficult for the family member to refuse as a gift in these circumstances.

De Oliveira-Cardoso *et al.* (2010:918) state that bone marrow donation entails diverse psychological implications for the sibling donor, who experiences stressful events such as the sibling's illness, the treatment decision, the discovery of compatibility and the responsibility of being the donor. Pamphilon *et al.* (2009:73) found that psychological consequences are poorly understood. Peripheral blood stem cell (PBSC) donation remains an invasive procedure and detailed donor counselling in relation to both physical and psychological aspects of the procedure are vital (Favre, Beksac, Bacigalupo, Ruutu, Nagler, Gluckman, Russell, Apperley, Szer, Bradstock, Buzyn, Matcham, Gratwohl & Schmitz, 2003:878).

Whedon (1991:302) identified that numerous studies confirmed some long term psychological effects on marrow donors of patients who died as a result of BMT. Mood changes, lack of self-esteem, altered relationships and guilt have been identified as long-term sequences based on the donor's perception of the success or failure of the marrow transplant. Williams, Green, Morrison, Watson and Buchanan (2003:6) reported that the long-term effects on the donor if their sibling dies in spite of their PBPC donation could be devastating and donors need to be prepared for the possible poor outcome for the recipient.

The experience of pain is part of the stem cell donation process whereby the donor is confronted with procedures in which they have to endure pain. Madjar (1998:39) describes that pain imposes its presence as requiring one's attention, not only by its intensity, but also by its spatiality. Invasive procedures such as percutaneous needle

biopsies (insertion of a hollow needle through the skin and other overlying tissue for the purpose of withdrawing a small specimen of tissue for laboratory analysis), needle aspirations (withdrawal of fluid from a cyst or body cavity through a hollow needle) may be potentially or frankly painful or carry the risk of painful complications. The distress that such procedures cause and the lack of habituation to related pain and anxiety may account for a patient's reluctance to have some procedures repeated or their aversion to further therapy (Madjar, 1998:9). Clare, Mank, Stone, Davies, Potting and Apperley (2010:98) identified that psychosocial factors associated with stem cell donation is from within the family despite relatively high levels of pain associated with donation. None of the donors in their study asked for treatment to be stopped and also their sense of moral obligation was stronger.

The main motivation for related donors to donate bone marrow is the fact that they are placed potentially as the saviour of the life of a family member. Therefore, donors associated the act of donation with 'saving somebody's life'. Despite the fear and ambivalence that mark the desire to donate bone marrow it becomes difficult for them to refuse. The responsibility can become overwhelming and therefore lead to psychological distress and symptoms of anxiety. This sense of moral obligation is stronger within family units (Clare *et al.*, 2010:98; De Oliveira-Cardoso *et al.* 2010:917). Donors identified that the method of identification and selection of sibling donors did not protect the donors' interest because this gave the donor little opportunity to refuse (Williams *et al.*, 2003:6).

Clare *et al.* (2010:97) reported that the inconvenience and discomfort associated with stem cell donation are subjectively limited in the donors' experience, suggesting that the concepts of 'gift' of donation and familial 'solidarity' partly compensate for pain and psychological stress.

However, some donors are feeling privileged to be able to give their stem cells to their brother or sister whilst others react in the opposite manner. Some of the compatible sibling donors verbalized that they are the black sheep of the family or that they were never close as brothers and sisters. Chang, McGarigle, Koby and Antin (2003:63) reported that the physical healthy bone marrow donor has not received much psychological attention, particularly if the donor is related to the recipient. It is likely that it is the very nature of the relationship the related donor has to the recipient that renders the process of donation more complicated.

Concerns have also been expressed about the experience of being a donor of healthy marrow. The issues addressed include confidentiality, as well as the psychological

adjustment of donors. The confidentiality of the donor was at odds with the principle of beneficence or promoting good to the potential recipient. The merits, for or against disclosure revolve around the ability of an unrelated transplant to succeed, coercion of the donor, autonomy of the donor to refuse to donate marrow, as well as the confidentiality of the donor (Whedon, 1991:356). Williams *et al.* (2003:6) found that the management of sibling donors in relation to the lack of confidentiality was contrary to voluntary donor participation in blood donation or in unrelated bone marrow donor registry. They identified that the donors have to be seen and counselled by clinicians independent of those treating the recipient. The voluntary status of donors is an important aspect of donation and underpins several principals of the transplantation process, such as a person's right to freely choose whether or not to participate in treatment and to be correctly informed of their consent to treatment (Clare *et al.*, 2010:100).

Most concerns have focused on the adverse psychological situation a donor may be in if the recipient experiences serious complications which cause suffering or death (Whedon, 1991:356). Wolcott, Wellisch, Fawzy and Landsverk (1986:487-488) found that if the recipient deteriorates or dies, the donor often feels that it is not his or her body that failed but "my body failed my sibling". Thus donor guilt is great. According to Christopher (2000:699), related family members worked together to support the donor and the recipient, however when relationships were not supportive, donors described feelings of frustration, resentment and anger.

Wood and Jacobs (1989:69) identified that strong psychological support was derived by integrating medical and nursing services into a multidisciplinary health care team. Furthermore, it is noted that the professional nurse is sensitive to patient anxieties and many questions about treatment details such as red cell transfusion, administration of chemotherapy programmes, irradiation and bone marrow transplantation, side-effects and survival are directed to her who is involved with moment-to-moment care.

Leitner, Baumgartner, Kalhs, Biener, Greinix, Hoecker and Wore (2009:362) reported that rhG-CSF mobilization, as well as subsequent PBPC collection is shown to be well tolerated in the short- and long-term profiles in their cohort of sibling donors and had no negative influence on the health status and quality of life (QoL) in the majority of them.

### **2.3.2 Economic factors**

In the beginning of the donation process potential donors raised concerns about who would pay for expenses such as the medical cost, travelling and accommodation. In addition, financial issues emerged and donors often requested financial support for

travelling. Smith Glasgow and Bello (2007:374) reported that participants raised concerns regarding payment for expenses related to medical coverage, compensation for days lost from work for donating bone marrow and care of family members, especially children. Gratwohl and Baldomero (2009:423) reported that due to cost considerations countries with limited resources make use of a HLA identical sibling donor as the preferred choice.

Whedon (1991:357) identified the ethical dilemma of allocation of resources that arises with procedures such as bone marrow transplantation that represent current high-cost technology. It was experienced that some leukemia patients were not eligible for transplants because of a lack of funds, therefore issues of justice will grow to have larger and larger importance in ethical decision making as it relates to bone marrow transplantation.

### **2.3.3 Administrative process**

Related donors may have different motivations for considering the haematopoietic stem cell donation from unrelated donors. They may be subjected to increased emotional and physical stress associated with donation. To ensure unbiased evaluation and counselling of individuals intending to donate, whether it is to a related or an unrelated recipient, donor evaluation should be done by a clinician who is not involved in the care of the prospective recipient (Horowitz & Confer, 2005:474).

According to Christopher (2000:699) there should be open communication between doctors and donors and the information on the donation procedure, hospitalization and the recovery phase should be based on the donors' desire for detailed explanation. To supplement verbal explanations given by the doctor appropriate information such as written materials, library resources and cancer educational sites on the Internet should be available, including exemplars from other donors' experiences should be provided, which would potentially improve the likelihood of a positive donation experience. Williams *et al.* (2003:5-6) found that the written information given was inadequate for donor needs. It was originally produced for patients and did not cover issues such as descriptions of both methods or GCSF administration on healthy donors and its potential long-term effect.

A post-donation follow-up plan should clearly be arranged with the donor to ensure that alterations in recovery are identified and additional questions are answered (Christopher, 2000:699).

### **2.3.4 Nursing intervention**

Hader (2006:32-33) found that nursing staff can play a key role to improving education, clinical management and community awareness pertaining to organ donation. Although Nursing Education regarding organ donation has increased over the last decade, more intense education is still needed. Van Vuren (2006:111) identified that learning is one way that a person can adapt to the environment.

Nurses continue to lack knowledge regarding criteria for donation, clinically and psychologically managing a donor and skills required to deal with family members (Hader, 2006:33).

Bone marrow transplant medical and nursing staff become involved if the donor is a member of the patient's family who is present during the patient's hospitalization. They may feel a special need to reward and support the donor whose psychological health may vary according to the patient's physical status. Concerns may also be felt about the potential for coercion involving the donor's choice, especially if the patient's outcome is poor. It has been acknowledged that supporting family is difficult for the busy involved BMT team and even more difficult if the family includes the donor who stands by helplessly watching his loved one deteriorate as a result of receiving his marrow (Whedon, 1991:356-357).

McFarland, Wasli and Kelchner Gerety (1997:551- 571) reported that anxiety is a common problem in patients and it was proven that through education it can be treated effectively. Information should be provided before the patient encounters stressful situations. Fear is an uncomfortable, ominous feeling and a normal response to danger. Once the nurse identifies a nursing diagnosis of fear on the side of the donor the nurse must encourage the verbalization of feelings. This may help the patient lessen the intensity and duration of the powerful emotions. The nurse should listen actively while encouraging the patient to discuss a fearful event or situation and together with the patient the nurse should explore the source of the fear and evaluate the extent to which the patient's fear is valid. The nurse should provide emotional support for the fearful patient and refer him/her to the social worker.

## **2.4 CONCEPTUAL FRAMEWORK**

Gallagher Galbreath (2011:292-294) reported that a human is seen as an adaptive system whereby the person is in constant interaction with the environment. The characteristics of a system include inputs of stimuli and adaptation level, outputs as behavioural responses

that serve as feedback and control processes known as coping mechanisms. Therefore, the basis of the Roy Adaptation Model (RAM) is adaptation which is the process and outcome whereby thinking and feeling persons as individuals or in groups use conscious awareness and choice to create human and environmental integration. This model places emphasis on the purposefulness of life and the creative potential of the adaptive person and present nursing assessment and intervention. Adaptation is defined as a process of responding positively to environmental changes. This study will only focus on the person or individual.

Lopez, Pagliuca and Araujo (2006:262-263) reported that the RAM sees the person as a holistic and adaptive system. Man is seen as a bio-psychosocial being and is constantly interacting with his changing environment. The person is considered as being in contact with the environment from which he receives stimuli that demand responses which can be visualized through behaviour. A stimulus is everything that provokes responses and its categories are in focal, contextual and residual stimuli. The environment is viewed as all conditions, circumstances and influences that surround and affect the development and behaviour of the human adaptive system. The person attempts to respond to the demands such as physical, social and psychological changes made on him by the changing environment.

Roy described the person as an adaptive system who has internal processes for coping with change which is named the regulator and cognator for the individual and the stabilizer and innovator for groups (Barone, Roy & Frederickson, 2008:353-354). Lopez *et al.* (2006:262) mentioned that it is not possible to observe how these sub-systems, the regulator / stabilizer function directly, their evaluation can only be made indirectly through the behaviours of the individual that are divided into four adaptive modes which are the physical-physiological, self-concept, role function and interdependence. According to the RAM, nursing as a science and practice expands adaptive abilities and enhances person and environment transformation with the goal of promoting adaptation for individuals in the four adaptive modes thus contributing to health, quality of life and dying with dignity (Barone *et al.*, 2008:354).

Adaptation manifests through the four adaptive modes and is the basis for nursing assessment. This study will only focus on the Role Function and the Interdependence modes. Gallagher Galbreath (2011:302); Lopez *et al.* (2006:262) claim that the Role Function mode is a role that consists of a set of expectations of how a person in a particular position will behave in relation to a person who holds another position, such as a healthy person who becomes a bone marrow donor to save a person and in this case a



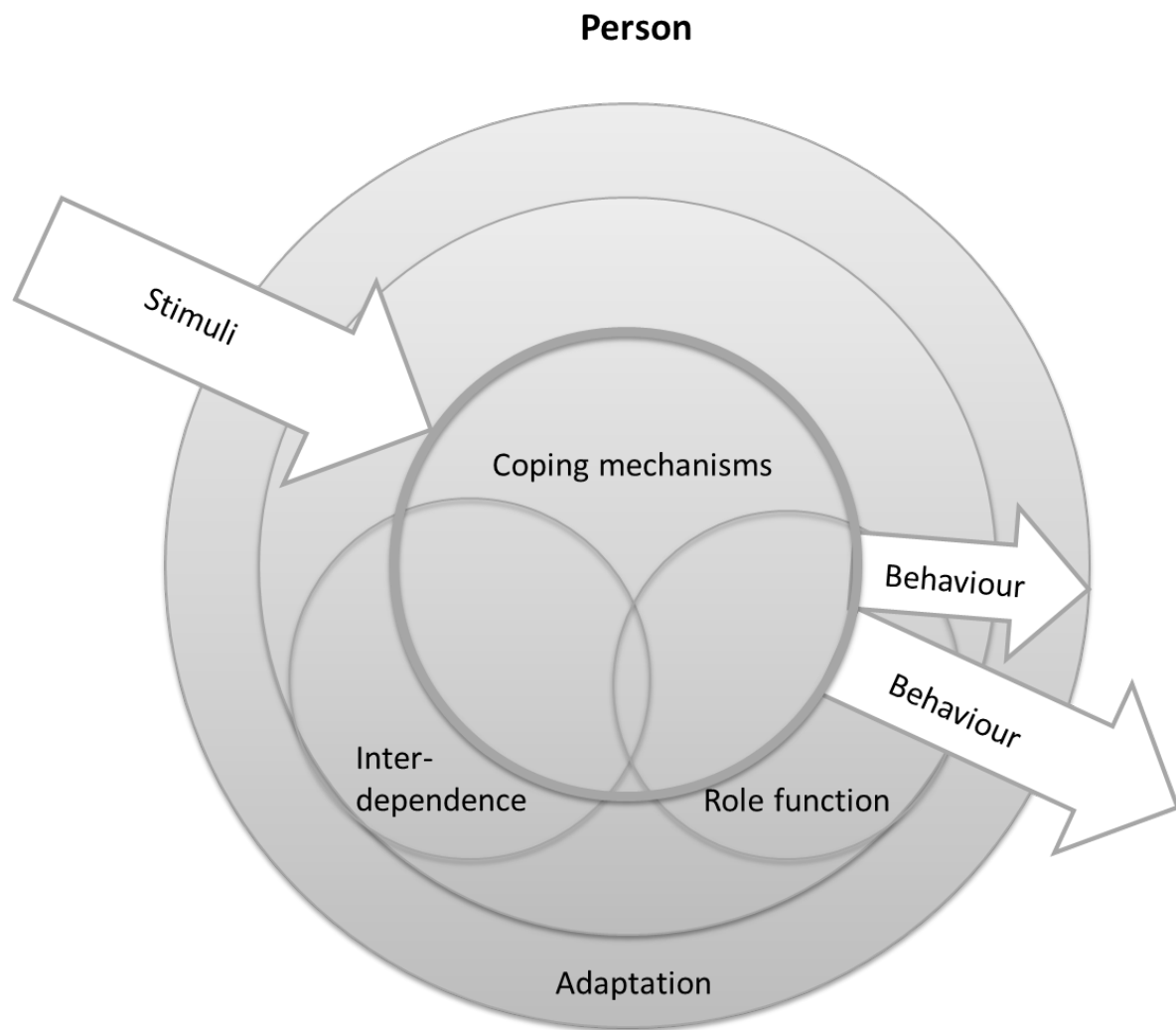
sibling who suffered a life threatening disease. The Interdependence Mode looks at relational integrity or security in nurturing relationships that focus on interactions related to love, giving and receiving, respect and value with significant others and support systems. Support systems are those who help the person meet their need for love, respect and value such as the nurse, family and friends.

The function of nursing then is to support and to promote patient adaptation. Gallagher Galbreath (2011:304-316) also report that the Roy Adaptation Model offers guidelines to the nurse to apply the nursing process. The nurse assesses the behaviour of the person by means of gathering the specific data through observations, careful measurement and by using an interview technique. The responses or output behaviour of the person as an adaptive system will be in relation to each of the adaptive modes. The nurse assesses internal and external stimuli that may be affecting behaviour such as stimuli that challenge the donor's ability to cope. Through the donor's behaviour the nurse also recognizes ineffective responses or adaptive responses that require nursing support. She then formulates a nursing diagnosis in relation to the adaptation status of the human adaptive system. Moreover, the nurse sets goals which involve making clear statements of the desired behavioural outcomes of nursing care. Then she plans the nursing intervention to alter and to manage stimuli so that it could fall within the person's ability to cope. The coping process of the person is the means of adaptation. The nurse evaluates to establish the effectiveness of the actions taken.

Therefore, it can be said that the RAM supports the notion that through the individual's use of its coping mechanism, psychosocial adaptation of the sibling donors can occur.

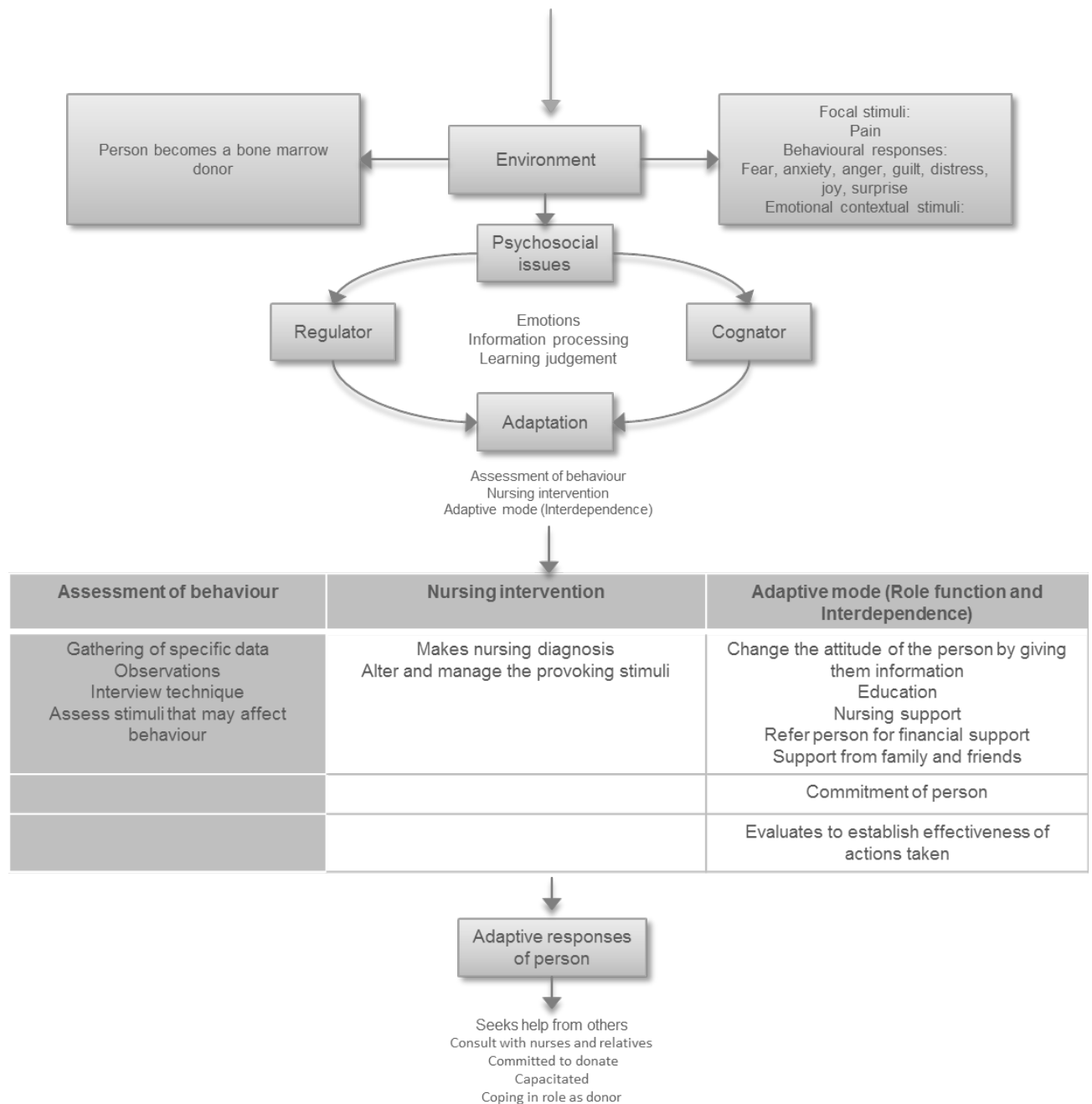
The following diagrammatical illustration that includes the two adaptive modes applicable to this study and the schematic presentation of the Roy Adaptation Model was done by the researcher.





**Figure 2.1: Diagrammatical illustration of the Roy Adaptation Model (as illustrated by the researcher)**

Figure 2.2 is a schematic summary of the conceptual framework:



**Figure 2.2: Schematic representation of Roy Adaptation Model (as illustrated by the researcher)**

## 2.5 SUMMARY

This chapter discussed the literature review undertaken on the psychosocial aspects that can be experienced by the siblings of patients that underwent allogeneic bone marrow transplantations. The literature review covered issues such as haematopoietic bone marrow donors, living donation, donor care in terms of psychological care, economic issues affecting the donors and the administrative process of the bone marrow donation procedure.

The conceptual framework is illustrated and provides an in-depth insight into the psychosocial issues experienced by the donors, the treatment that can be applied, as well as the adaptation process of the sibling bone marrow donor during bone marrow transplantation.

## **2.6 CONCLUSION**

Chapter three will provide an overview of the research methodology used to describe the psychosocial factors influencing the sibling donor during the bone marrow donation process.

## **CHAPTER 3:**

### **RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

This descriptive study aimed at describing the psychosocial and administrative effects the stem cell transplantation had on the sibling donors. In addition, this chapter will describe the research process as mentioned in chapter one. According to Fouché and Delport (2005:71) the research methodology simply means the way in which to solve a problem step by step. The purpose of this research was to describe the psychosocial factors that influenced the sibling donor during allogeneic bone marrow transplantation. The researcher identified the variables of psychosocial factors in the bone marrow donors.

The research question of the study entailed the psychosocial factors and administrative process which influence sibling donors during allogeneic bone marrow transplantations. A research questionnaire was distributed to 120 Haematopoietic Stem Cell sibling donors who were used to describe the psychosocial factors and administrative process that influence sibling donors during allogeneic bone marrow transplantation at a public sector hospital in Cape Town.

The objectives of this study were to determine:

- the psychosocial factors that influence sibling bone marrow donors
- whether the transplant team members explained the administrative process of the transplant in an understandable manner and language
- the effect of the psychosocial factors and administrative process of the allogeneic bone marrow transplantation on the sibling donors.

#### **3.2 RESEARCH METHODOLOGY**

##### **3.2.1 Research design**

A design is the blueprint for conducting a study that maximizes control over factors that could interfere with the validity of the findings. The research design gives the researcher greater control and thus improves the validity of the study. Variables are not manipulated and there is no treatment or intervention. Descriptive study designs are planned to gain more information about characteristics within a particular field of study.

A quantitative research approach with a descriptive design was used in the study, with four open-ended questions which were analysed qualitatively. It was used to help the researcher to have control over the study, to identify problems with the current bone marrow transplantation practice and to determine what other investigators in similar situations are doing (Burns & Grove, 2009:236-237). The researcher used multiple variables that reflect emotions such as acceptance, fear, stress, depression, dislike and concepts such as pain and failure to obtain an overall picture of the psychosocial factors as phenomena being examined.

The reason for not selecting a qualitative research methodology was due to the fact that many of the bone marrow donors resided outside of Cape Town, disallowing the researcher the available time or funding to pursue this method.

Files of adults over the age of 18 years were accessed for contact information from Groote Schuur Hospital, a public health sector bone marrow transplant unit.

### **3.2.2 Population and sampling**

The population for the purpose of this research refers to a particular type of individual, such as stem cell donors. The target population is the entire set of individuals who meet the sampling criteria (Burns & Grove, 2009:343-344). The target population for this study is all Haematopoietic Stem Cell (HSC) sibling donors.

Sampling means taking any portion of a population that is considered to be representative of that population or universe. The term sampling implies that it is a smaller section or a set of individuals selected from a population (Strydom, 2005:193). The sample for this study was obtained at a single institution namely Groote Schuur Hospital, renowned for its fully fledged bone marrow transplantation programme in the public health sector in South Africa. The researcher made use of full population sampling as the sample size was small. The sample is heterogeneous in character that enables the researcher to increase generalizability of the findings (Burns & Grove, 2009:228). The sample was obtained by accessing the database system for information of sibling donors of living and nonliving haematology patients who had undergone Haematopoietic Stem Cell Transplantation (HSCT) from the years 2000 until 2010. This was done as there were an insufficient number of sibling allogeneic stem cell transplantations per year at the research institution and due to the fact that most of the donors resided outside the Western Cape Metropole region. The total population of this study consisted of (N=143).

The sample size of 120 (N=120) bone marrow sibling donors became eligible for this study. LoBiondo-Wood and Haber (2010:239) reported that the researchers can encounter problems in recruiting the appropriate number of subjects for a study. In this study not all donors had telephonic contact details which essentially became a problem. The researcher sent out 120 questionnaires to the potential participants and only 64 completed questionnaires returned that gives a 53.3% participation rate. A number of 33 (n=33) of the contactable donors refuse to participate after agreeing to have questionnaires mailed to them by the researcher.

#### *3.2.2.1 Inclusion criteria*

- the donor should be over 18 years of age
- sibling male and female bone marrow donors
- siblings who are able to comprehend and communicate their understanding of the bone marrow donation process in English and Afrikaans
- living within the borders of South Africa.

#### *3.2.2.2 Exclusion criteria*

Mentally incapacitated donor and two prisoners were excluded.

### **3.3 INSTRUMENTATION**

A self-report questionnaire is a type of data-collection method that requires subjects to respond directly to either interviews or structured questionnaires about their experiences, behaviours, feelings or attitudes. Questionnaires, like interviews may be open-ended or close-ended. The researcher developed a questionnaire which was based on the literature reviewed, the research objectives and her experience to collect the data from the sibling bone marrow donors inquiring about the psychosocial factors that influenced them, experiences during the donation process and whether the transplant team members explained the administrative process of the transplant in an understandable manner and language. A self-reporting questionnaire is an accepted form of data collection for this study (LoBiondo-Wood & Haber, 2010:274-275) and the researcher designed the questionnaire with the assistance of the research experts in the clinical field, a research methodologist and a statistician. The questionnaire consisted of three sections of which section A involved the biographical details, section B (psychosocial details) which focused on three subcategories which was general, behavioural and financial (economics) information and section C focused on the administrative process.

The questionnaires were mailed to the participants. The advantages of mailed questionnaires according to Delport (2005:167) are:

- the cost is relatively low
- the respondents enjoy a high degree of freedom in completing the questionnaire
- information can be obtained from a large number of respondents within a brief period of time.

### **3.3.1 The questionnaire**

Questionnaires are used in descriptive studies to describe an identified area of concern (Burns & Grove, 2009:239). The basic objective of a questionnaire is to obtain facts and opinions about a phenomenon from people who are informed on the particular issue (Delport, 2005:166).

#### **3.3.1.1 *Format of the questionnaire***

The questionnaire consisted of a covering letter, a demographics page, a six point Likert-scale with the range of scores from 1 to 6 which indicated response options of strongly disagree, disagree, mildly disagree, mildly agree, agree and strongly agree and yes/no (dichotomous) questions. The covering letter served to introduce and explain the research to the participants (Delport, 2005:170). The questionnaire included demographic data, knowledge of the transplantation process, information received regarding the transplantation and donation process and the experiences of the donor during and after the donation process. It consists of sections: A, B and C. In addition, four open-ended questions were used to obtain information of psychosocial issues in terms of behaviour, pre-donation preparation and economic issues in the participants own words.

### **Section A: Demographic Data**

Demographic data includes information that describes important characteristics about the subjects in a study (LoBiondo-Wood & Haber, 2010:277). The demographic data collected in this study were gender, ethnic group, as well as employment, educational level and age group at the time of transplantation, as well as their current age group. According to the Higher Education Act 101 of 1997 (Republic of South Africa, 1997) the terminology “Grade 12” means the highest grade in which education is provided by a school as defined in the South African Schools Act 84 of 1996 (Republic of South Africa, 1996) and “Higher education” means all learning programmes leading to qualifications higher than grade 12 or its equivalent in terms of the National Qualifications Framework as contemplated in the South African Qualifications Authority Act 58 of 1995 (Republic of South Africa, 1995) and includes tertiary education as contemplated in Schedule 4 of the Constitution.

## **Section B: Psychosocial data with three open-ended questions**

These questions were close-ended, dichotomous in nature and open-ended questions.

The questions were used to identify the knowledge, attitudes, beliefs, feelings and experiences of the respondents.

- Questions (1–7), the information the respondents received regarding the patient's disease, as well as the donation process
- Questions (8–14) how the donation process affected the respondents physically
- Questions (15–21) how the donation process affected the respondents emotionally
- Questions (22–26), the respondents' behavioural responses during the donation process
- Questions (29–35), the financial impact the donation process had on the respondents at the time of transplant
- Open-ended questions were formulated: two focused on the psychosocial impact and one on the economic situation

## **Section C: Administrative data with one open-ended question**

These questions were close-ended with one open-ended question.

These questions were formulated to identify how the transplant team executed the administrative process.

- Questions (37–42) focused on the administrative process of the donation process

Variables are listed in a table below.



**Table 3.1: Variables**

Independent	Dependent
Demographic (Gender, Age, Education, Employment)	Economics (Employment, Expenses) Administrative (Information, Support )

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The researcher regularly followed up with the participants, as well as with the postal company to establish whether the research packets arrived at their destination, which was done in order to ensure an increase in the response rate. To increase the response rate an addressed stamped envelope was enclosed in the research packet (Delport, 2005:167-172). The researcher estimated that it would take the respondent 30 minutes to complete the questionnaire.

#### 3.3.2.1 *Validity*

Delport (2005:160-161) identified that the validity of a measurement procedure is the degree to which the measurement process measures the variable it claims to measure and that the concept is measured accurately. Content validity is concerned with the representativeness or sampling adequacy of the content of an instrument. To determine content validity the researcher must ensure that the instrument really measures the concept and that it provides an adequate sample of items that represent the concept. The measuring instrument for this study was developed by the researcher to address the concept of this research study. Face validity is concerned with the superficial appearance or face value of a measurement procedure. For instance, does the measurement technique look as if it measures the variable that it claims to measure.

The content of the questionnaire represented the topic of the psychosocial and administrative issues experienced by the sibling bone marrow donors in a developing country. A nursing research specialist, research methodologist and a statistician and the researcher's clinical experience in haematology / oncology nursing contributed to the validity of the measuring instrument.

#### 3.3.2.2 *Reliability*

The reliability of a measurement procedure is the stability or consistency of the measurement which signifies that if the same variable is measured under the same conditions, a reliable measurement procedure will produce identical or nearly an identical

measurement (Delpont, 2005:162-163). It is important to test the reliability of an instrument before using it in a study because a reliable instrument enhances the power of a study to detect significant differences or relationships actually occurring in the population under study (Burns & Grove, 2009:337).

A pilot study was conducted that made use of the measuring instrument to establish the validity and the reliability of the research questionnaire. The respondents in the pilot study did not indicate any difficulty in completing the questionnaire. The same instrument was used for the main study.

### **3.4 PILOT STUDY**

LoBiondo-Wood and Haber (2010:236) defined a pilot study as a small sample study conducted as an introduction to a larger scale study. However, pilot studies are used to develop various steps in the research process, for example to develop and to refine an intervention or treatment, a measurement method, a data collection tool or the data collection process (Burns & Grove, 2009:44). Clark-Carter (2010:35) indicates that it is of particular importance to conduct a pilot study when you are using measures which have been developed by yourself, such as a questionnaire. In this research the pilot study was used to refine the data collection tool (questionnaire). According to Strydom (2005:209) the entire questionnaire should be pretested with individuals who are representative of the target population.

Ten participants ( $n=10$ ) 8.3% from the total population ( $N=120$ ) were selected to test the questionnaire. The research packets were sent by registered mail to the ten participants. After resending the research package to one participant she then refused to participate after agreeing, therefore 9 questionnaires were returned. The outcome of the pilot study indicated to the researcher that the respondents did not have any difficulties in completing the questionnaire, therefore no changes to the questionnaire were needed. The results of the pilot study are included in the results of the study.

### **3.5 DATA COLLECTION**

According to Burns and Grove (2009:441) data collection is a process of selecting subjects and using steps such as observing, testing, measuring, questioning, recording or a combination of these methods to gather data from the subjects. The researcher was solely responsible for distributing and collecting the questionnaires. Ethical approval to conduct the study was obtained from the Health Research Ethics Committee of Stellenbosch University, as well as from the ethics research board of the participating

institution and the Department of Health Provincial Government of the Western Cape. Following this, the researcher accessed the database system and obtained the contact details of the target population.

The researcher contacted the sibling donors who had legitimate telephone numbers and invited them to participate in the study. The researcher explained to the participants the purpose of the research and at the same time informed them that the questionnaire and consent form will be posted. The researcher sent both the informed consent form and the survey to be completed to those participants who were unable to be contacted by phone.

Burns and Grove (2009:445-6) argue that data collection can be both joyful and frustrating. Consequently, during the period of telephonically contacting the participants, the researcher learned that four of the participants died, others expressed emotions of anger towards the transplant team, others expressed their gratitude towards the transplant team and there were others that just needed to talk to someone that had an insight in the bone marrow donation process. The participants who agreed to partake in the study, (n=16) later refused and (n=17) failed to follow through whilst twenty three (n=23) research packets were unclaimed from the postal service company. The researcher collected the data for the pilot and main study over a period of fifteen weeks instead of eight weeks as proposed. The researcher experienced problems during the data collection period and continued the data collection process for a longer period in order to achieve an adequate sample size (Burns & Grove, 2009:442). Problems were such as some participants refused or encountered difficulty in collecting the package from the postal service, others took a long time to collect the package which resulted that the return rate of the questionnaires was too slow.

According to Delport (2005:167) the cost of mailed questionnaires is relatively low, on the contrary the researcher spent more funds than was budgeted for due to the increase in postal service and postage.

### **3.6 DATA ANALYSIS**

- Data analysis is a process that reduces, organises and gives meaning to data. Descriptive techniques include measures of central tendency, such as mean, median and mode, measures of variability such as range and standard deviation (SD).
- The mean is the arithmetical average of all the scores by adding all of the values in a distribution and divide by the total number of values. The mean is generally

considered the single best point for summarising data when using interval- or ratio-level data.

- The median is the score where 50% of the scores are above it and 50% of the scores are below it and it can be used with ordinal-, interval- and ratio-level data.
- The standard deviation (SD) measure of variability is based on the concept of the normal curve. In this study descriptive statistics of the quantitative data were used that allowed the researcher to organise the data in ways that gave meaning and insight and to examine the phenomenon from a variety of angles (Burns & Grove, 2009:44-470; LoBiondo-Wood & Haber, 2010:310-318).

According to Kruger, De Vos, Fouché and Venter (2005:218) the researcher should construct a data analysis plan that will guide the researcher to do the interpretation of the data and the results, hence a statistician is consulted who has access to many available statistical software programs. The statistician linked the data collection scales to a MS Excel spread sheet which allowed the researcher to capture the quantitative raw data on computer. The statistician organised the data in frequency tables and histograms. MS Excel and STATISTICA Version 9 StatSoft Inc. (2009) STATISTICA (data analysis software system) were used to analyse the data and the missing data was statistically and graphically replaced by using the software program Imputation.

The analysis of the four open-ended questions was based on content analysis. Burns and Grove (2009:528) defined it as the means of measuring the frequency, order or intensity of the occurrence of words, phrases or sentences. Content analysis uses counting, it is concerned with meanings, intentions, consequences and context.

The statistical concept probability, addresses statistical analysis as the likelihood or probability of obtaining the results that is being done in a concrete study and it is expressed as  $p$ . The level of significance is the cut-off point on the theoretical normal curve at which the results of statistical analysis indicate a statistical significant difference between two groups. In nursing studies, the level of significance is usually set at 0.05 or rather a probability of 0.05 (5%) is used and is expressed as  $p$ -value (Terre Blanché, Painter and Durrheim. 2006:216-220; Burns & Grove, 2009:451-459). Similarly, according to Clark-Carter (2010:146-147) probability is frequently set at .05 and the symbol is  $\alpha$  (the Greek letter alpha) which gives you an indication if the outcome of the research is in the rejection region or rather its probability is outside the rejection region, then the outcome of the research is not statistical significant.

According to Bowers (2008:142-164) almost all clinical research begins with a question, for example, what psychosocial factors influence sibling donors during allogeneic bone marrow transplantations. To answer questions like this the researcher has to transform the research question into a testable hypothesis called the null hypothesis. The hypothesis tests are prominent in general clinical research of which the chi-square test is one of them. The chi-square test is applied to frequency data in the form of a contingency table. In this study this chi-square test was applied to compare two categorical variables to establish relationships between them. If the p-value associated with the chi-square test is less than 0.05, the researcher can reject the null hypothesis and conclude that the two variables are not independent or rather, there is a statistical significant difference in the proportions.

Missing data were seen because some respondents failed to complete certain questions and no patterns were observed because they were randomly spread throughout the data set. Those respondents were still included in the study to prevent the sample size from reducing and consequently affect the power of the statistical test. The approach of mean imputation will only be graphically displayed since the missing data will be used to describe the sample (Clark-Carter, 2010:358-359).

The researcher entered the raw data of the open-ended questions into a MS Excel spread sheet and further managed the data by giving each subject a number to ensure which scale belonged to which subject (Burns & Grove, 2009:406-447).

### **3.7 ETHICAL CONSIDERATIONS**

Terre Blanche *et al.* (2006:61) identified that the essential purpose of research ethics is to protect the welfare of the research participants. Participation in this study was voluntary.

The data collection occurred after the project was approved by the Health Research Ethics Committee of Stellenbosch University, as well as from the ethics research board of the participating institution and the Department of Health Provincial Government of the Western Cape. The contactable sibling donors were informed in advance of the objectives of the study and provisional consent was obtained. All questionnaires were accompanied by a consent form that assured subjects of anonymity and that all the information they gave would be kept confidential. Participants were given a code number, therefore the researcher could conclude that the data were processed anonymously.

The completed questionnaires were kept safe and secure in a manually locked cupboard in order to protect the confidentiality of the data. The researcher, academic supervisor and statistician had access to the collected data.

### **3.8 LIMITATIONS**

The researcher experienced various problems before and during the data collection process. Firstly (n=46) of the legible donors' telephone numbers were none existing which made it impossible for the researcher to connect with them. The time frame of this process in terms of the participants in both the pilot and main study had to be extended by seven weeks due to the speed of the postal service delivery, as well as the participant's availability to collect it at the postal depot.

The researcher's original plan was to send out all research packets via registered mail in order to keep track of the research packets. However, some contactable participants refused or were unable to collect the research package from the post office and asked it to be resent by normal mail. The researcher solved this problem by mailing the research packets directly to those contactable participant's postal or residential addresses (Burns & Grove, 2009:442). In other cases some participants misplaced it and asked for it to be resent. As a consequence, the researcher spent more money on this process than it was budgeted for.

### **3.9 SUMMARY**

In summary the research methodology applicable to this study was described. Steps taken to ensure the quality and trustworthiness of the research data were described. The design was used to define structures within which the study is implemented and also to find a solution to the research question. Quantitative statistical analysis will be described and discussed in greater detail in the following chapter.

## **CHAPTER 4:**

# **PRESENTATION, ANALYSIS AND INTERPRETATION OF RESEARCH FINDINGS**

### **4.1 INTRODUCTION**

In this chapter, the analysis of the close-ended questions and the four open-ended questions obtained during this study will be described. The purpose of this study was to describe the objectives as mentioned in chapter 1. These objectives are to describe the psychosocial factors that influence sibling donors during allogeneic bone marrow transplantations, whether the transplant team members explained the administrative process of the transplant in an understandable manner and language and the effect of the psychosocial factors and administrative process of the allogeneic bone marrow transplantation on the sibling donors.

Data collection was undertaken by the researcher by utilising a self-report questionnaire which consisted of three sections. Section A entailed the demographic data of the respondents. Section B consisted of the psychological and social information and Section C focused on the administration process. Section B and C consisted of the four open-ended questions that addressed the in-depth experiences of the donors during and after the donation process.

A full population sample of 120 (N=120) respondents were utilised from January 2000 to December 2010 comprising only from one institution, a public sector hospital in Cape Town. The final sample inclusive of the pilot study consisted of a total of (n=64) (53%) respondents who completed and returned their questionnaires, whilst (n=23) (19%) questionnaires were returned back to the sender due to changes in addresses and no collection at the post office. A refusal rate of (n=33) (28%) was identified, but the respondent rate of 53% was still satisfactory and whereby Delport (2005:167) and Clark-Carter (2010:74) indicated that the response rate of mailed questionnaires is normally low, often around 30%.

### **4.2 DATA ANALYSIS METHOD**

First, descriptive statistics were used for describing the sample. Clark-Carter (2010:116) reports that the first phase of quantitative data analysis is to provide a summary of the data in the study, by describing the data numerically or graphically. After the researcher entered the raw quantitative data on a MS Excel spread sheet, the statistician organised

the data in frequency tables and histograms. In addition, certain variables were compared. The independent variables used were demographic (employment, education and age at time of transplantation) and only section B of the questionnaire dealing with the psychosocial information of the sibling bone marrow donor during the bone marrow donation process. Burns and Grove (2009:179) identified that these demographic variables described the sample and will also determine the population for generalisation of the findings.

#### **4.3 DESCRIPTION OF STATISTICAL ANALYSIS**

The descriptive statistics used to describe the variables included frequency distributions in the form of histograms and frequency tables, measures of central tendency such as mean and median and standard deviation (SD).

The Pearson chi-square statistical analysis test was used to test for relationships amongst groups.

During the data analysis process of the four open-ended questions the data was also analysed using content analysis quantitatively. The data are communicated numerically.

#### **4.4 PRESENTING THE STUDY FINDINGS**

##### **4.4.1 Section A: Demographic data**

A detailed description of donor demographics and donation specific characteristics of the 64 respondents are presented from table 4.1 to table 4.6.



**Table 4.1: Gender**

Category	Frequency (f)	Percentage (%)
Female	29	45
Male	34	53
Missing	1	2
<b>Total</b>	<b>n=64</b>	<b>100</b>

Forty-five percent of the respondents (n=29) were female, 53% (n=34) were males who participated in the study. Two percent (n=1) had not answered the question.

**Table 4.2: Ethnicity**

Category	Frequency (f)	Percentage (%)
Coloured	36	56
White	17	27
African	6	9
Indian	4	6
Missing	1	2
<b>Total</b>	<b>n=64</b>	<b>100</b>

At the time of donation the sample was predominantly Coloured 56% (n=36), 27% (n=17) were White, 9% (n=6) were African and the smallest group 6% (n=4) were Indian. Two percent of the respondents (n=1) did not provide their ethnic group. The results of the ethnic groups have been compared with the data from the General Population of 2007 (Statistics South Africa, 2007:25). The Coloured people are in the majority in the Western Cape where the bone marrow transplant centre is situated which is 61% of the overall population.

**Table 4.3: Employment at the time of transplantation**

Category	Frequency (f)	Percentage (%)
Employed	37	58
Self-employed	4	6
Unemployed	17	27
Scholar	5	8
Missing	1	1
<b>Total</b>	<b>n=64</b>	<b>100</b>

At the time of transplantation most of the respondents 58% (n=37) were employed, 6% (n=4) were self-employed, a large number of respondents 27% (n=17) reported that they were unemployed, 8% (n=5) were scholars and 1% (n=1) were missing data. The employment level was compared to the general population of 2007. In the Western Cape, during 2007 it indicated that 64% females and 63% males were employed, according to the Descriptive community survey 2007 (Statistics South Africa, 2007).

**Table 4.4: Educational level at the time of transplantation**

Category	Frequency (f)	Percentage (%)
Higher	13	20
Grade 12	12	19
Other grade	24	37
No Schooling	5	8
Missing	10	16
<b>Total</b>	<b>n=64</b>	<b>100</b>

In terms of education, a high percentage 37% (n=24) of respondents completed only certain grades at school and 19% (n=12) completed high school. After completion of high school 20% (n=13) respondents indicated that they obtained a higher education. However, only 8% (n=5) of respondents claimed that they had no schooling and (n=10) 16% failed to answer.

**Table 4.5: Age group at time of transplantation**

Category	Frequency (f)	Percentage (%)
60 – 65	2	3
50 – 59	12	19
30 - 49	34	53
18 - 29	9	14
0 - 17	5	8
Missing	2	3
<b>Total</b>	<b>n=64</b>	<b>100</b>

The median age of the donors is described as follow, the respondents range in age from 0 to 65 years (mean age = 37 years) at the time of transplant. The mean from the frequency distribution was calculated as given in Clark-Carter (2010:415). This is an indication that at the time of the transplant more than 50% of the respondents were in the age group of 30 to 49 years of age 53% (n=34), 14% (n=9) were in the age group of 18 to 29 years of age, 19% (n=12) were in the age group of 50 to 59 years of age, two respondents 3% (n=2) were in the age group of 60 to 65 years and 8% (n=5) respondents were in their school aged (0-17) years. Two respondents 3% (n=2) did not complete this question.

The age level of 31 to 35, 36 to 40, 41 to 45 and 46 to 50 resulted in 24%. This is an indication that only 24% of South Africans falls into the age group of 31 to 50 years and this was compared to the general population of 2007 (age by geography), (Statistics South Africa 2007:62).

**Table 4.6: Current age group**

Category	Frequency (f)	Percentage (%)
67	1	2
60 – 65	8	12
50 - 59	15	23
30 - 49	26	41
18 - 29	12	19
<b>Missing</b>	<b>2</b>	<b>3</b>
<b>Total</b>	<b>n=64</b>	<b>100</b>

The respondents who completed and returned their questionnaires ranged in age from 18 to 67 years (mean age = 42 years). The mean from the frequency distribution was calculated as given in Clark-Carter (2010:415). It shows that over the period of 10 years the age group 30 to 49 is still the dominant group 41% (n =26), 2% (n=1) is 67 years of age, 23% (n=15) are in the age group of 50 to 59, 19% (n=12) are in the age group of 18 to 29, 12% (n=8) are in the age group of 60 to 65 and 3% (n=2) were missing data.

#### 4.4.2 Quantitative data / Close-ended questions

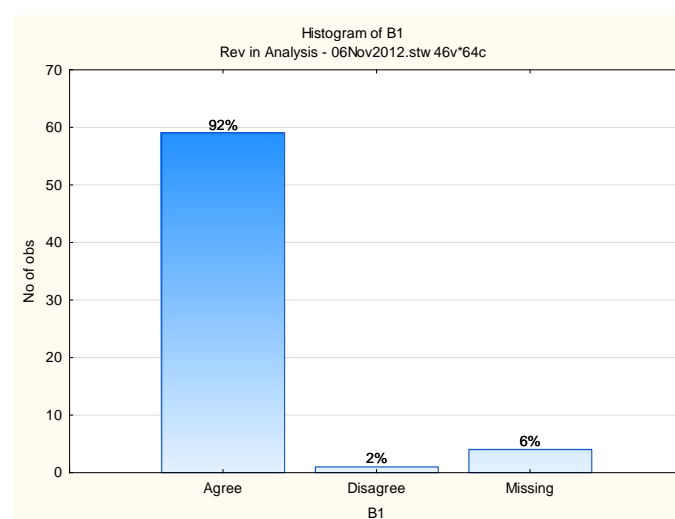
##### 4.4.2.1 Section B: Psychosocial data

This section of the questionnaire was structured to determine whether the sibling bone marrow donors experienced psychological and social issues during the donation process. A six point Likert scale was incorporated where participants had to rank the degree that influenced their experience, as well as yes / no (dichotomous) questions. The results were reported as percentages, the quantitative data were presented in a collapsed form of agree and disagree.

#### Subcategory 1: General information

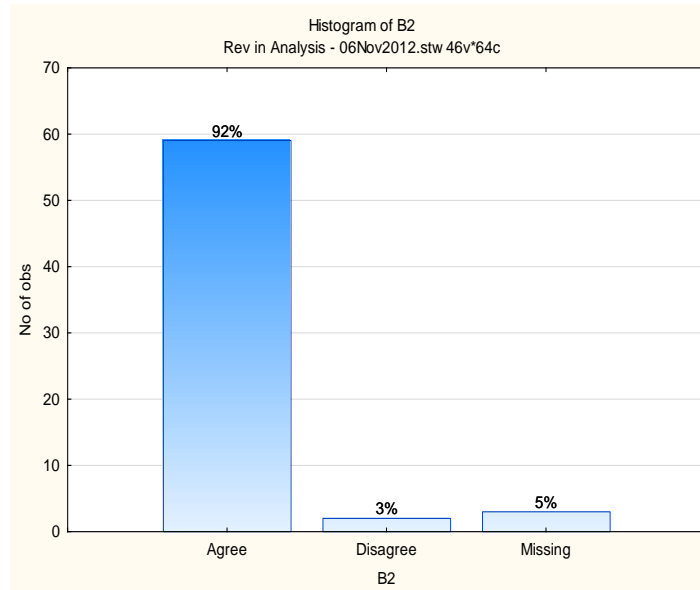
This sub-section focuses on:

1. The information the respondents received regarding the patient's disease, as well as the donation process
2. How the donation process affected them physically
3. How the donation process affected them emotionally



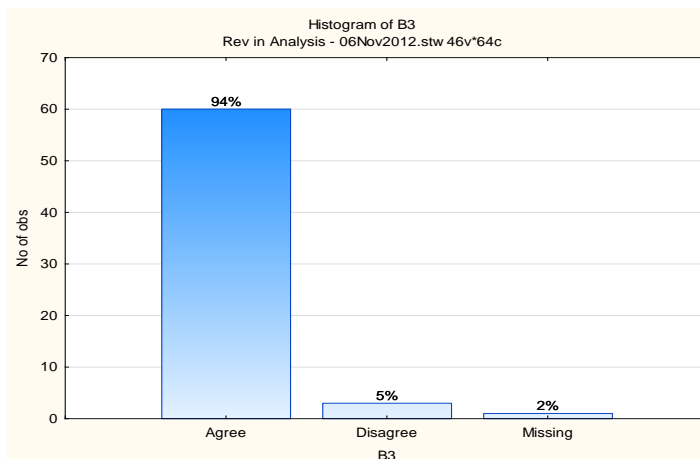
**Figure 4.1: Question 1 - The doctor explained what was wrong with your sister or brother**

The explanation of the doctor regarding the recipient's medical condition featured prominently 92% (n=59), only one 2% (n=1) respondent disagreed that the doctor explained to him/her and 6% (n=4) had not responded to the question.



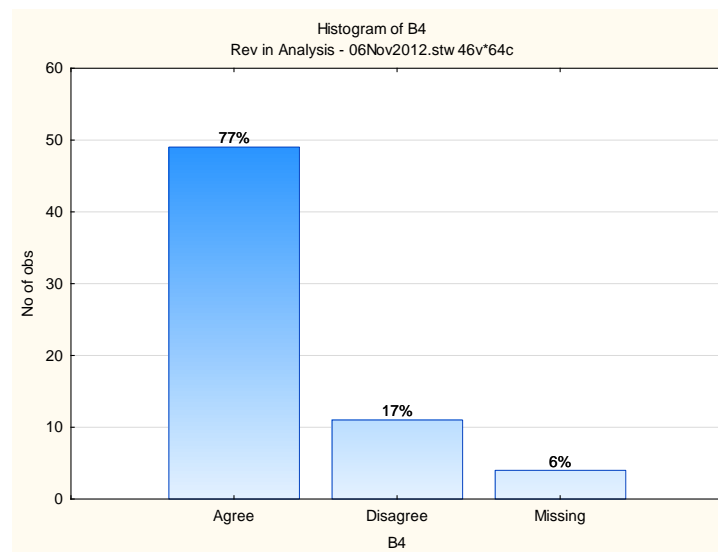
**Figure 4.2: Question 2 - You understood the doctor's explanations**

A positive outcome of the donation process identified by the respondents 92% (n=59) that they understood the doctor's explanation, very few 3% (n=2) did not and 5% (n=3) had not responded to the question.



**Figure 4.3: Question 3 - You understood why you were going to donate bone marrow**

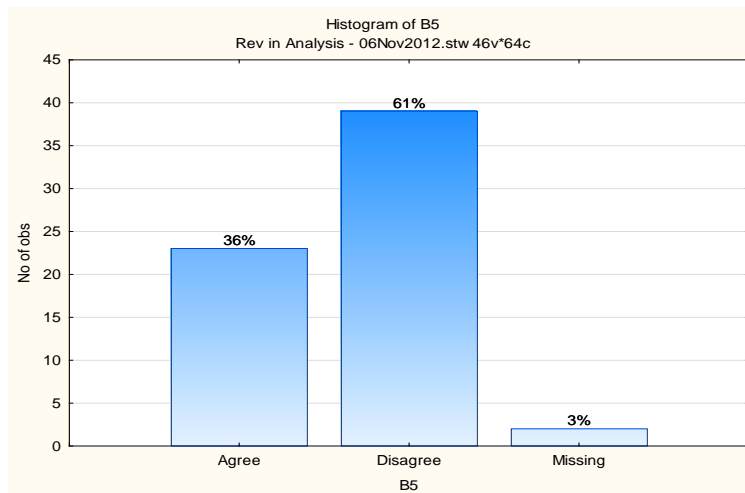
The understanding of the respondents as to why they donated their bone marrow featured prominently 94% (n=60), a few 5% (n=3) had no idea why they donated and 1% (n=1) had not responded to the question.



**Figure 4.4: Question 4 - You understood the counsellor's explanations**

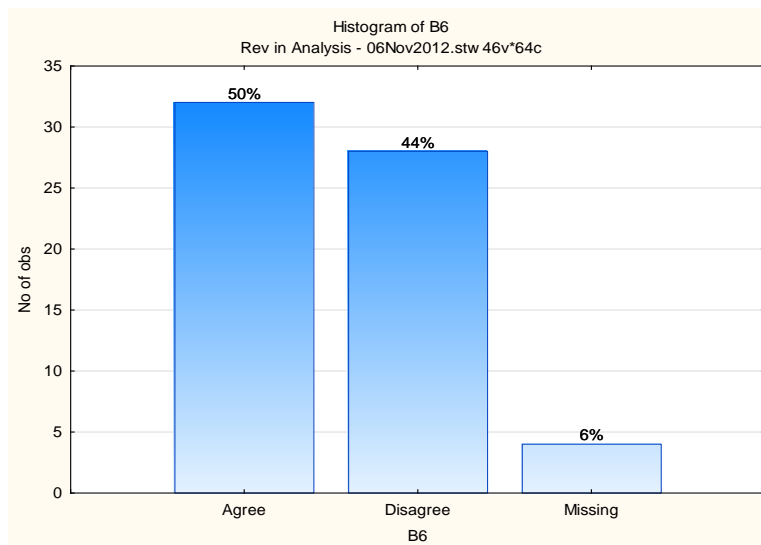
An overwhelming majority of respondents understood the counsellor's explanation 77% (n=49), a few 17% (n=11) had not and 6% (n=4) of respondents had not provided an answer. Peripheral Blood Stem Cell (PBSC) donation remains an invasive procedure and detailed donor counselling in relation to both physical and psychological aspects of the procedure is vital (Favre *et al.*, 2003:878).

Five respondents that were in the age group 0 to 17 years at the time of the transplant claimed that they understood the doctor's and counsellor's explanation given. MacLeod, Whitsett, Mash and Pelletier, (2003:229) reported that children's experience of the events surrounding HSCT, their recall of those events and their impressions of their own reactions to those events would likely be affected by their age both at the time of transplant and at the time of the research.



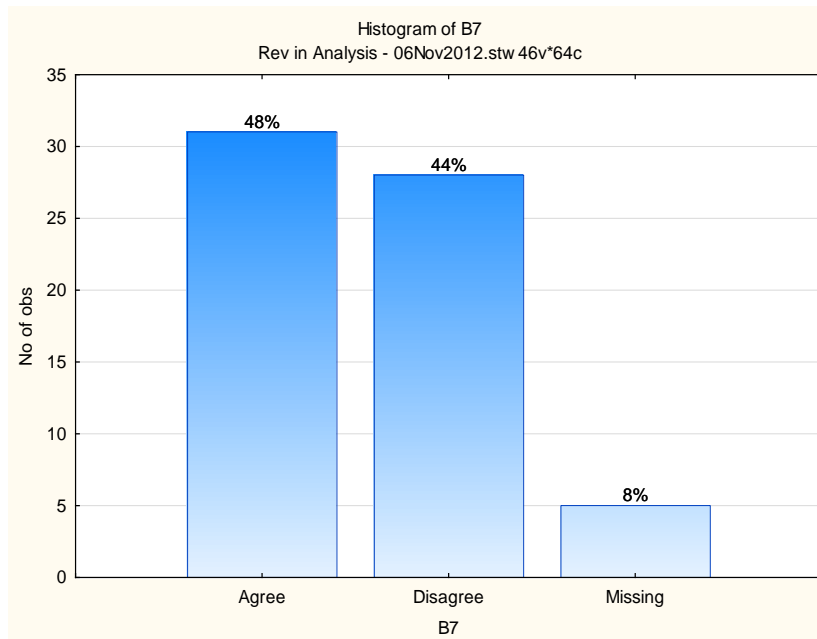
**Figure 4.5: Question 5 - You were scared of donating part of your body**

The minority of respondents 36% (n=23) were scared of donating part of their body, the majority 61% (n=39) were not and 3% (n=2) respondents had not provided an answer.



**Figure 4.6: Question 6 - You were scared of the bone marrow biopsy**

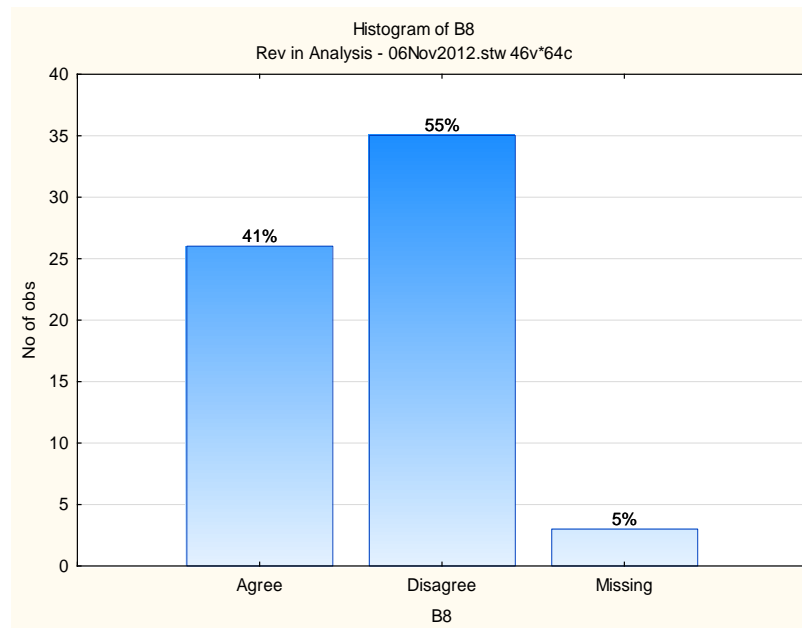
Fifty percent of the respondents 50% (n=32) were scared of having a bone marrow biopsy, 44% (n=28) disagreed and 6% (n=4) respondents had not answered the question. Wiener *et al.* (2008:306) identified that even without the risks of anaesthesia and surgery used in conventional bone marrow (BM) harvest, peripheral blood stem cell (PBSC) donors still felt anxious about the procedure and expressed concerns about physical harm to themselves and their sibling recipient. According to Gallagher Galbreath (2011:297) anxiety is a result of ineffective individual coping related to an input stimuli.



**Figure 4.7: Question 7 - You were scared of injecting yourself**

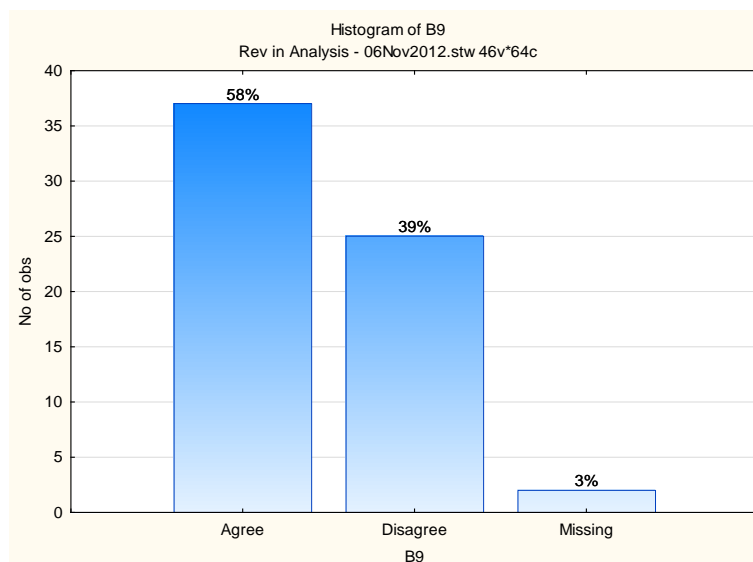
Most respondents 48% (n=31) were scared of injecting themselves, 44% (n=28) disagreed and 8% (n=5) had not answered the question. The blood cell donors in this study experienced high anxiety before the procedure that was not due to lack of information and communication with medical staff, since nearly all donors declared themselves satisfied by the explanation given to them by the doctors, nurses and social worker. In fact 50% (n=32) were scared of having the bone marrow biopsy and 48% (n=31) were scared of injecting themselves. According to Fortanier *et al.* (2002:148) levels of anxiety before the collection procedure were fairly high in both blood cell and bone marrow groups of donors.





**Figure 4.8: Question 8 - You were scared when your groin swelled up because of the leg catheter**

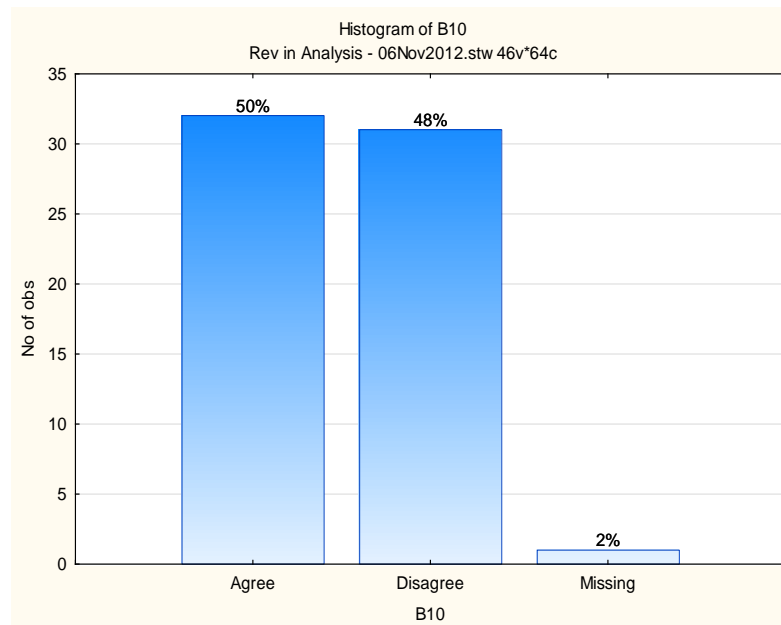
A substantial number of respondents 41% (n=26) were scared when they experienced being bruised or developed a haematoma at the venous access site, the majority of respondents 55% (n=35) indicated that they were not and 4% (n=3) respondents had not answered the question.



**Figure 4.9: Question 9 - You felt pain when the bone marrow biopsy was being done**

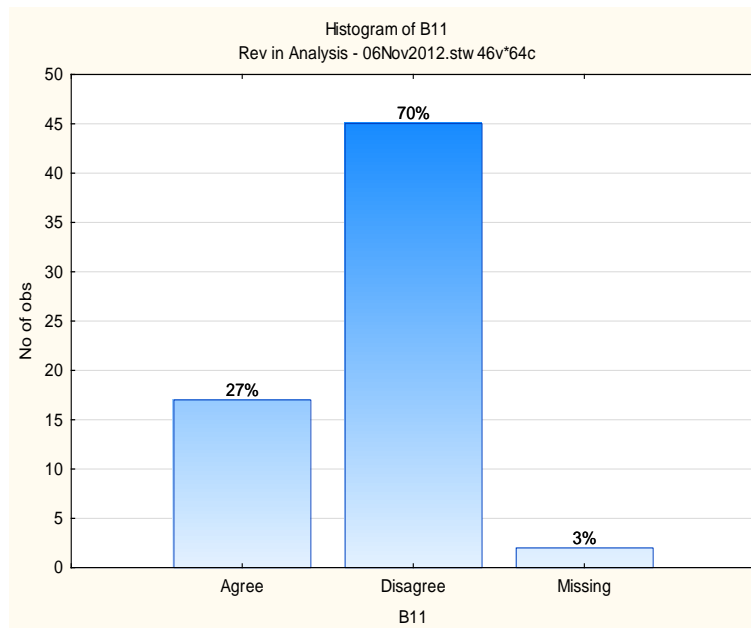
The results show that 58% (n=37) of respondents experienced pain when the bone marrow biopsy was done, 39% (n=25) had not experienced pain and 3% (n=2) had not

responded to the question. What sets inflicted pain apart from pathological pain resulting from disease is the wounding nature of inflicted pain. It is not only that the invasive procedures that puncture, pierce, cut or tear living tissue are themselves wounding, but more specifically the pain resulting from such procedures is also wounding (Madjar, 1998:154).



**Figure 4.10: Question 10 - You felt bone pain because of the injection**

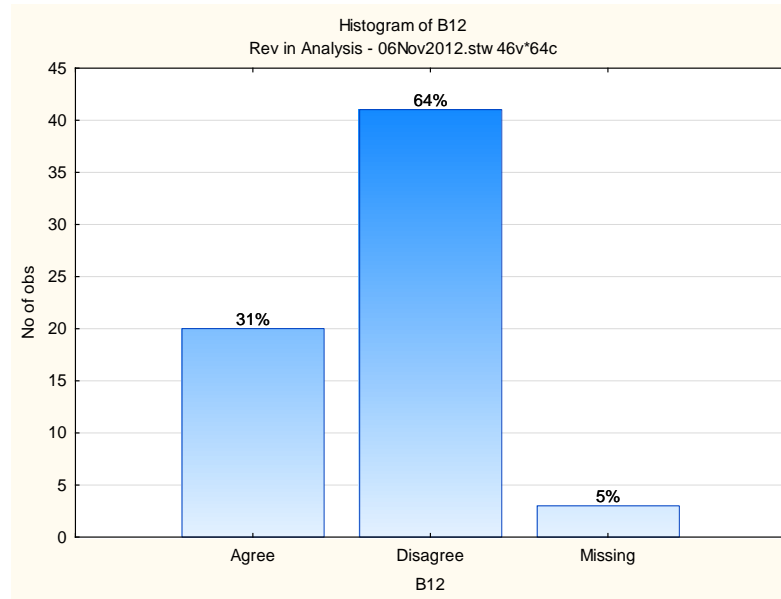
More respondents experienced symptoms such as bone pain related to granulocyte colony-stimulating factor (G-CSF) injection. Thirty two 50% (n=32) reported that they experienced bone pain following the injections, 48% (n=31) experienced no bone pain and 2% (n=1) had not provided an answer to the question. Favre *et al.* (2003:878) identified that adverse events experienced by healthy PBSC donors following stem cell mobilization with G-CSF include bone pain, headache and fatigue. The review of Siddiq, Pamphilon, Burnskill, Doree, Hyde and Stanworth (2009) identified that peripheral blood stem cell donors experienced more pain prior to donation which may be related to the pre-donation administration of G-CSF.



**Figure 4.11: Question 11 - You had headaches because of the injection**

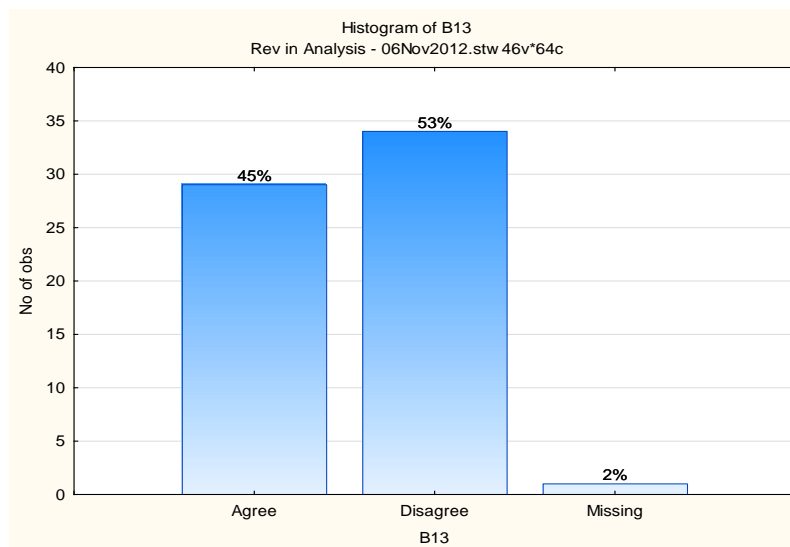
A few of the respondents experienced headaches 27% ( $n=17$ ) because of the injection, the majority 70% ( $n=45$ ) had not experienced headaches and 3% ( $n=2$ ) of respondents had not provided an answer.

In contrast to previous literature, fewer ( $n=17$ ) respondents in this study experienced headaches because of the (G-CSF) stimulation. Fortanier *et al.* (2002:148) confirmed that no harvest procedure is free from pain and anxiety for healthy donors. The result of that study also confirmed that (G-CSF) stimulation is the most painful part of the harvesting procedure for blood cell donors. The pain is in the form of headaches and bone pain. However, Van Vuren (2006 143) argued that pain is a subjective and highly individual experience and that the interpretation and meaning of pain involve various psychosocial and cultural factors.



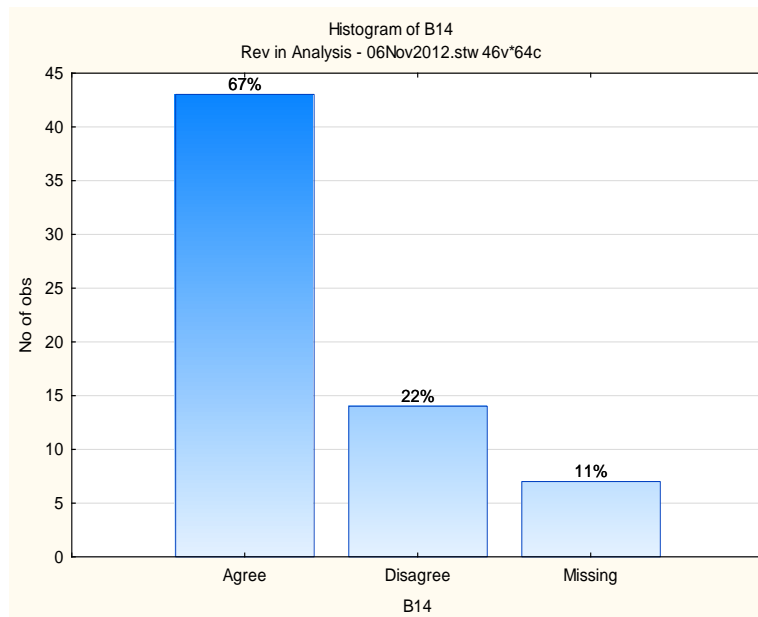
**Figure 4.12: Question 12 - You couldn't sleep at night**

Insomnia appeared in the accounts of 31% (n=20) of respondents, whilst most of the donors 64% (n=41) had not experienced sleeplessness. Three 5% (n=3) had not answered the question.



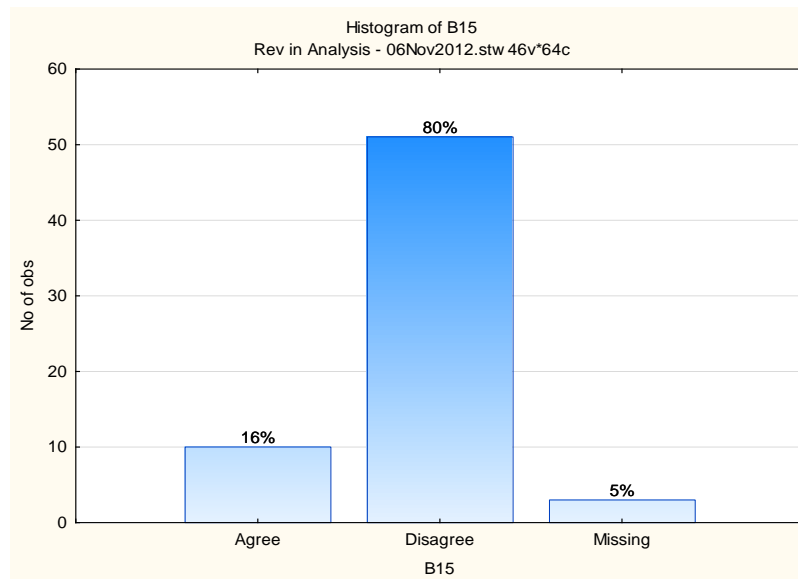
**Figure 4.13: Question 13 - You felt stressed when you stayed in the hospital**

More than half of the respondents 53% (n=34) were not stressed being hospitalised, whilst 45% (n=29) were stressed and one 2% (n=1) did not answer this question.



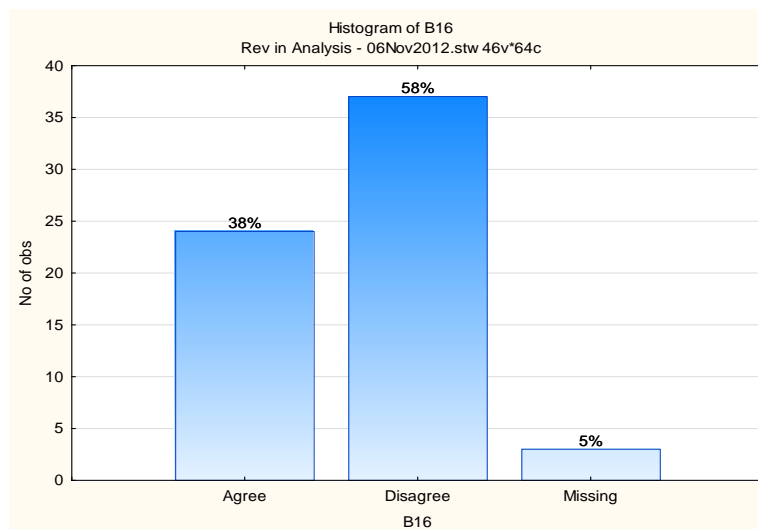
**Figure 4.14: Question 14 - In your culture you are allowed to donate part of your body**

From the cultural aspect, most 67% (n=43) respondents indicated that it was allowed according to their cultural beliefs to donate a part of their bodies, 22% (n=14) felt challenged by their cultural beliefs and 11% (n=7) did not complete this question. Of the (n=57) respondents that answered this question, (n=12) were White and (n=45) fell in the other ethnic groups. Smith (1998:33) reported that transplantation reveals cultural values that are assigned to a person's body and challenges assumptions concerning the body and personal identity. The outcome of this result is contrary to what was found by Smith Glasgow and Bello (2007:374) that African Americans were more private about their bodies and did not belief in donating organs.



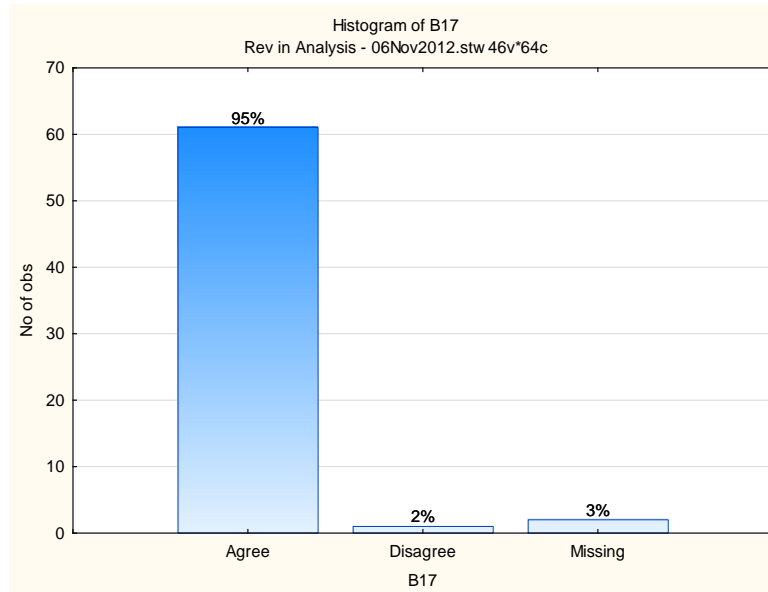
**Figure 4.15: Question 15 - People avoided you after the whole process**

A few respondents 15% (n=10) indicated that they were avoided by people after the donation of their stem cells, a large number 80% (n=51) disagreed and 5% (n=3) had not provided an answer.



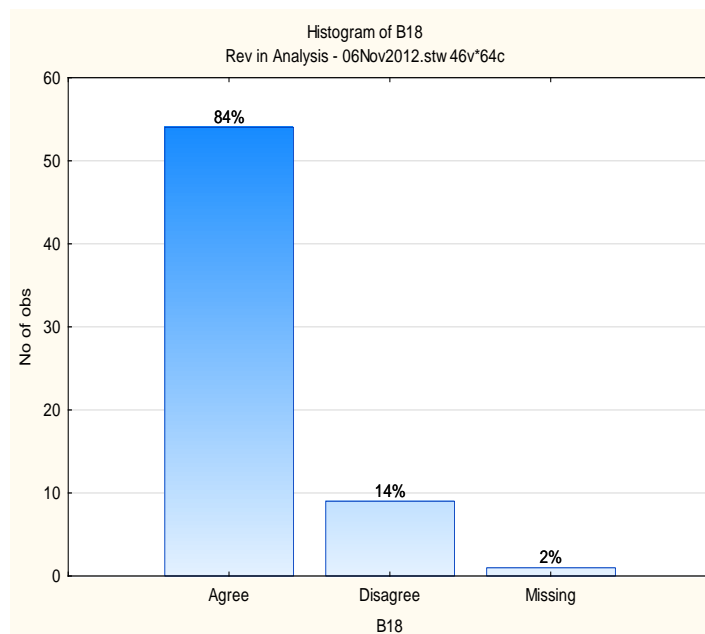
**Figure 4.16: Question 16 - It was difficult for your family when you were away from home**

Some of the respondents 37% (n=24) indicated that it was difficult for their family when they spent time away from home, more than half of the respondents' family had not experienced any difficulty 58% (n=37) and 5% (n=3) had not answered the question.



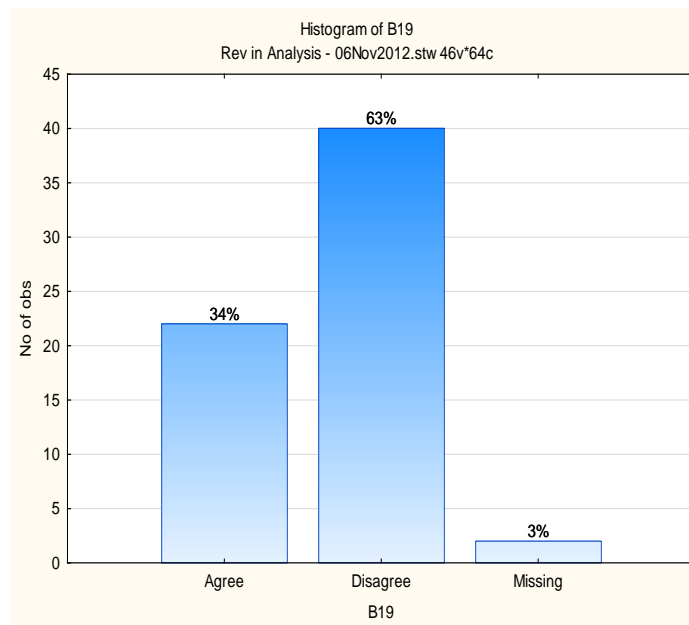
**Figure 4.17: Question 17 - Your family supported you through the whole process**

Family support for the respondents featured prominently 95% (n=61), only one respondent 2% (n=1) felt that he received no support from his family and 3% (n=2) had not answered the question. Smith (1998:35) identified that a lack of family support may add to the donor's psychological suffering.

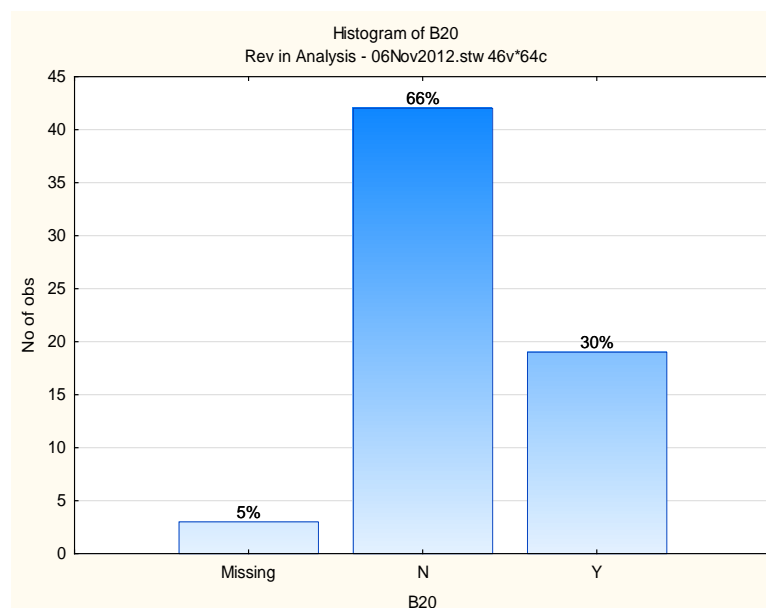


**Figure 4.18: Question 18 - You felt healthy six months after the whole process**

An overwhelming majority of respondents 84% (n=54) felt healthy six months after the donation process, 14% (n=9) of respondents disagreed and 2% (n=1) of respondents had not responded to the question.

**Figure 4.19: Question 19 - Your lifestyle changed because of the whole process**

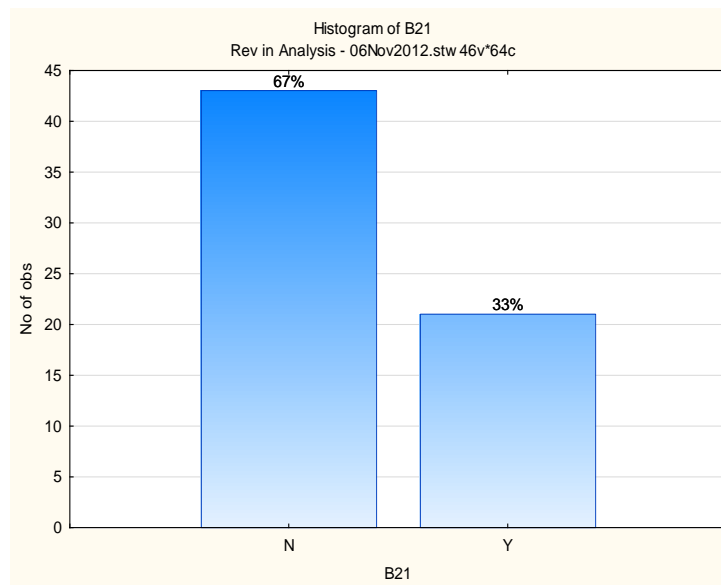
Twenty two respondents 34% (n=22) experienced lifestyle changes because of the donation process, the majority did not 66% (n=40) and 3% (n=2) of respondents did not answer the question.





**Figure 4.20: Question 20 - Your lifestyle changed a lot because of the whole process**

The lifestyles of some respondents 30% (n=19) changed a lot because of the donation process, the majority 65% (n=42) indicated that there were no lifestyle changes and 5% (n=3) of respondents did not answer the question.

**Figure 4.21: Question 21 - You felt stressed after the whole process because you couldn't be active immediately**

The majority of respondents 67% (n=43) had not experienced stress due to inactivity after the donation process and 33% (n=21) felt stressed because of inactivity due to the donation process.

The findings of questions (18 - 21) demonstrated similarly to what has been cited in Favre *et al.* (2003:878) that through PBSC donation the procedure is safe and somewhat less of a burden in terms of donor quality of life as reflected by the duration of hospitalisation associated with the collection procedure and the number of days of restricted activity for post bone marrow harvesting.

**Table 4.7: Information the respondents received regarding the patients' disease, as well as the donation process**

Question	Number of respondents	Agree	Disagree	Missing
1. The doctor explained what was wrong with your sister or brother	60	92%	2%	6%
2. You understood the doctor's explanation	61	92%	3%	5%
3. You understood why you were going to donate bone marrow	63	94%	5%	1%
4. You understood the counsellor's explanation	60	77%	17%	6%
5. You were scared of donating part of your body	62	36%	61%	3%
6. You were scared of the bone marrow biopsy	60	50%	44%	6%
7. You were scared of injecting yourself	59	48%	44%	8%

As table 4.7 indicates, respondents experienced anxiety due to fear of the invasive procedures such as the bone marrow biopsy and by injecting themselves.

**Table 4.8: How the donation process affected the respondents physically**

Question	Number of respondents	Agree	Disagree	Missing
8. You were scared when your groin swelled up because of the leg catheter	61	41%	55%	4%
9. You felt pain when the bone marrow biopsy was being done	62	58%	39%	3%
10. You felt bone pain because of the injection	63	50%	48%	2%
11. You had headaches because of the injection	62	27%	70%	3%
12. You couldn't sleep at night	61	31%	64%	5%
13. You felt stressed when you stayed in the hospital	63	45%	53%	2%
14. In your culture you are allowed to donate part of your body	57	67%	22%	11%

Respondents experienced pain when the bone marrow biopsy was done, as well as bone pain related to granulocyte colony-stimulating factor (G-CSF) injection.

The physical symptoms experienced by the respondents were not influenced by the variables education, employment and age at the time of transplant, hence no significant differences were detected in the physical domain. See table below for the chi-square test results.

**Table 4.9: Physical domain data**

<b>Psychosocial data / General information/ Physical</b>	<b>Number of respondents</b>	<b>Statistics / Pearson Chi-square</b>	<b>Df</b>	<b>p</b>
You were scared when your groin swelled up because of the leg catheter / x Employment	60	1.216016	df=3	p=.74917
You were scared when your groin swelled up because of the leg catheter / x Education	52	.9890693	df=3	p=.80390
You were scared when your groin swelled up because of the leg catheter / x Age group at transplant	59	3.007790	df=4	p=.55652
You felt pain when the bone marrow biopsy was being done / x Employment	61	3.294154	df=3	p=.34846
You felt pain when the bone marrow biopsy was being done / x Education	52	1.504179	df=3	p=.68131
You felt pain when the bone marrow biopsy was being done / x Age group at transplant	60	7.372139	df=4	p=.11748
You felt bone pain because of the injection / x Employment	62	6.582857	df=3	p=.08645
You felt bone pain because of the injection / x Education	53	1.399891	df=3	p=.70556
You felt bone pain because of the injection / x Age group at transplant	61	4.540446	df=4	p=.33778
You had headaches because of the injection / x Employment	61	1.919729	df=3	p=.58923
You had headaches because of the injection / x Education	53	.5684966	df=3	p=.90360

You had headaches because of the injection / x Age group at transplant	60	2.019796	df=4	p=.73212
You couldn't sleep at night / x Employment	60	.6642857	df=3	p=.88157
You couldn't sleep at night / x Education	53	1.076061	df=3	p=.78286
You couldn't sleep at night / x Age Group at Transplant	59	1.942986	df=4	
You felt stressed when you stayed in the hospital / x Employment	62	.1859527	df=3	p=.97982
You felt stressed when you stayed in the hospital / x Education	54	.3700233	df=3	p=.94636
You felt stressed when you stayed in the hospital / x Age Group at Transplant	61	3.106914	df=4	p=.54010
In your culture you are allowed to donate part of your body / x Employment	56	.2683223	df=3	p=.96587
In your culture you are allowed to donate part of your body / x Education	50	2.161778	df=3	p=.53952
In your culture you are allowed to donate part of your body / x Age Group at Transplant	55	1.120650	df=4	p=.89098

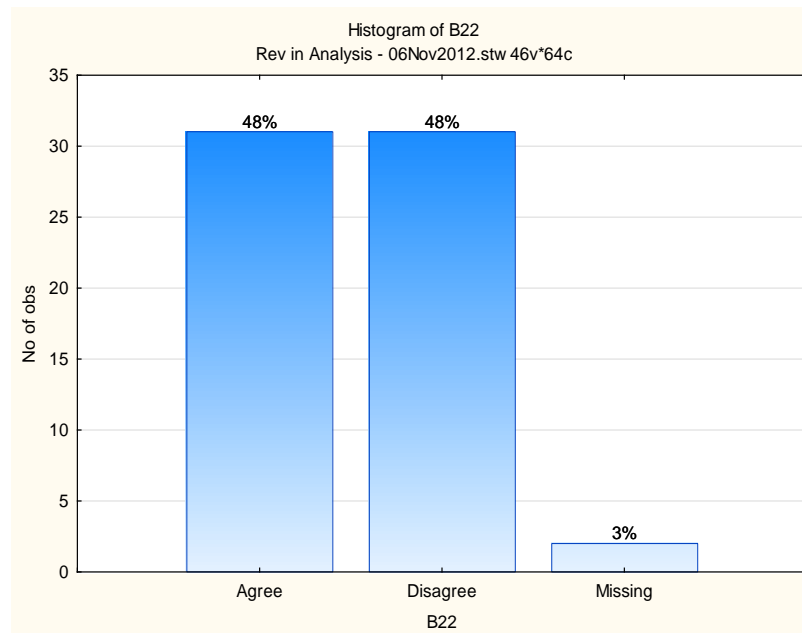
**Table 4.10: How the donation process affected the respondents emotionally**

Question	Number of respondents	Agree	Disagree	Missing
15. People avoided you after the whole process	61	15%	80%	5%
16. It was difficult for your family when you were away from home	61	37%	58%	5%
17. Your family supported you through the whole process	62	95%	2%	3%
18. You felt healthy six months after the whole process	63	84%	14%	12%
19. Your lifestyle changed because of the whole process	62	34%	63%	3%
20. Your lifestyle changed a lot because of the whole process	61	30%	65%	5%
21. You felt stressed after the whole process because you couldn't be active immediately	64	33%	67%	0%

The emotional wellbeing and quality of life of the respondents were not affected negatively.

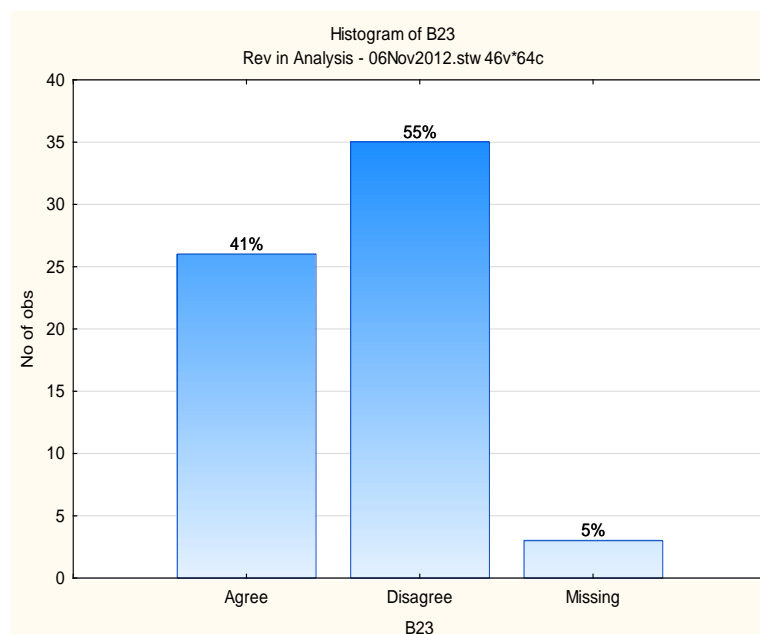
### **Subcategory 2: Behaviour**

This sub-section focuses on the respondent's behavioural responses during the donation process.



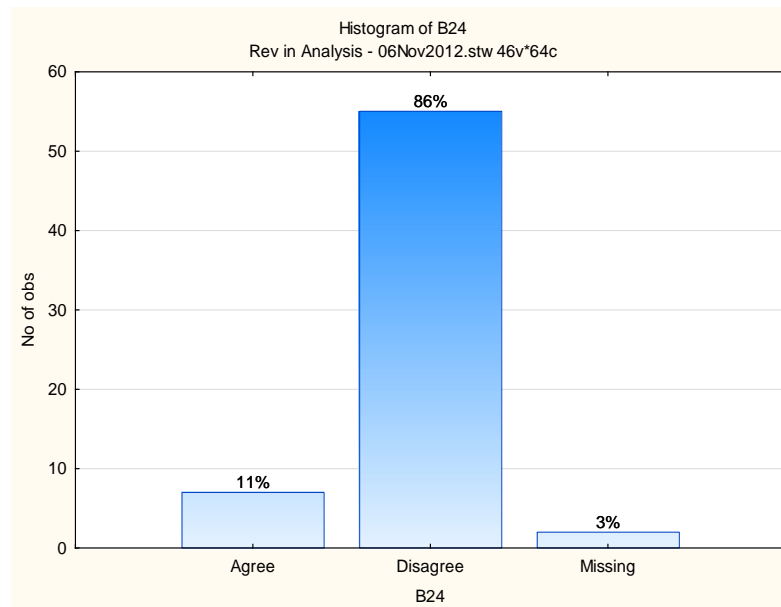
**Figure 4.22: Question 22 -You didn't feel good emotionally during the process**

Experiences of being a stem cell donor were associated with emotional feelings. Results revealed that the one half of the respondents found the experience positive and the other half negative. Exactly half of the respondents 48.5% (n=31) felt good about themselves and the rest experienced bad emotions during the donation process and 3% (n=2) of respondents did not answer the question. De Oliveira-Cardoso *et al.* (2010:917) reported that related bone marrow donors present negative emotional reactions which resulted from the stress triggered by the donation and its psychological implications.

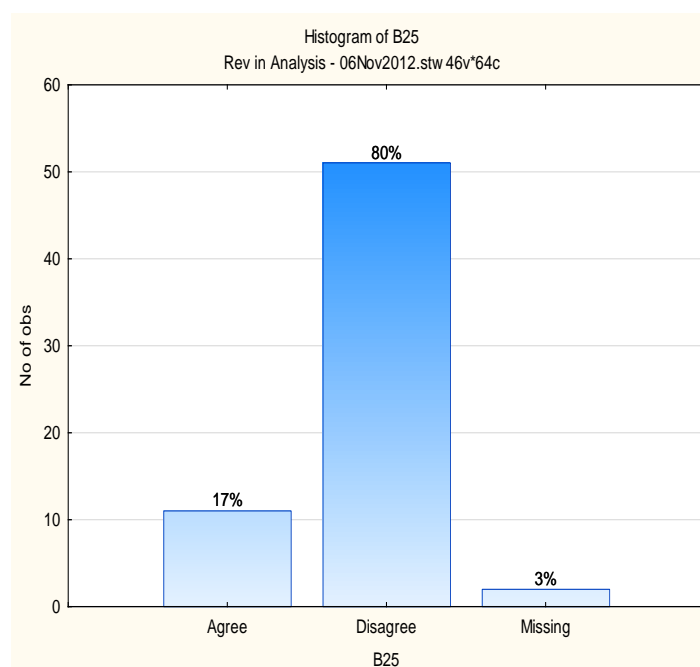


**Figure 4.23: Question 23 - You sometimes felt depressed during the process**

Depression occurred in 40% (n=26) of respondents during the donation process, more than half of the respondents 55% (n=35) were not depressed and 5% (n=3) did not provide an answer.

**Figure 4.24: Question 2 - You sometimes didn't want to cooperate with the transplant team**

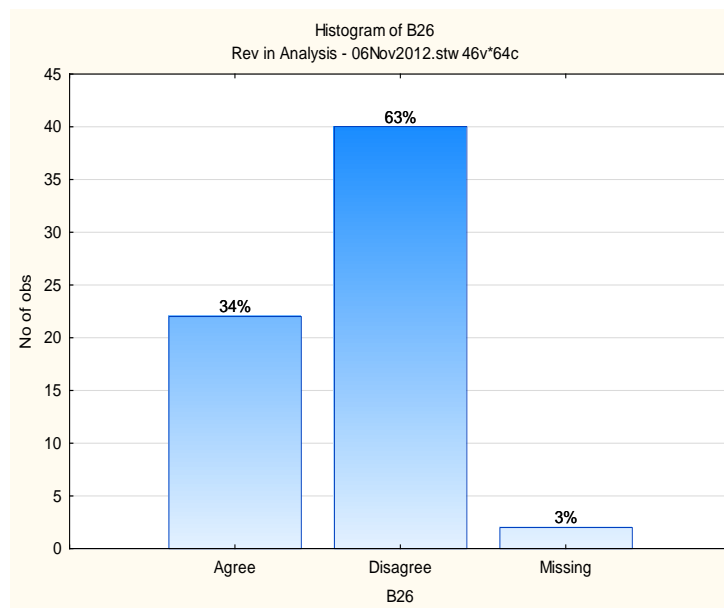
A few 11% (n=7) respondents indicated that they did not want to cooperate with the transplant team sometimes, the larger percentage of the sample 86% (n=55) did not refuse to cooperate and 3% (n=2) had not provided an answer to the question.





**Figure 4.25: Question 25 - You were scared of dying during the process**

Eleven 17% (n=11) of the (n=62) respondents experienced fear of their own death, 80% (n=51) were not scared of dying during the donation process and 3% (n=2) had not answered the question. The outcome of questions (23-26) is in contrast what to Wiener *et al.* (2007:7) identified that being a stem cell donor can be a stressful experience for pediatric siblings such as being at risk for depression, withdrawal, behavioural problems and lowered self-esteem.

**Figure 4.26: Question 26 - You disliked the procedure more and more**

A substantial number of respondents 34% (n=22) disliked the bone marrow donation process, a large number 63% (n=40) did not and 3% (n=2) did not provide an answer to the question. It is evident that negative behavioural control such as being uncooperative and attitudes such as dislikes were not the intentions by most of the donors in this study.

Clare *et al.* (2010:97) indicated that the inconvenience and discomfort associated with stem cell donation are subjectively limited in the donors' experience, suggesting that the concepts of 'gift' of donation and familial 'solidarity' partly compensate for pain and psychological stress.

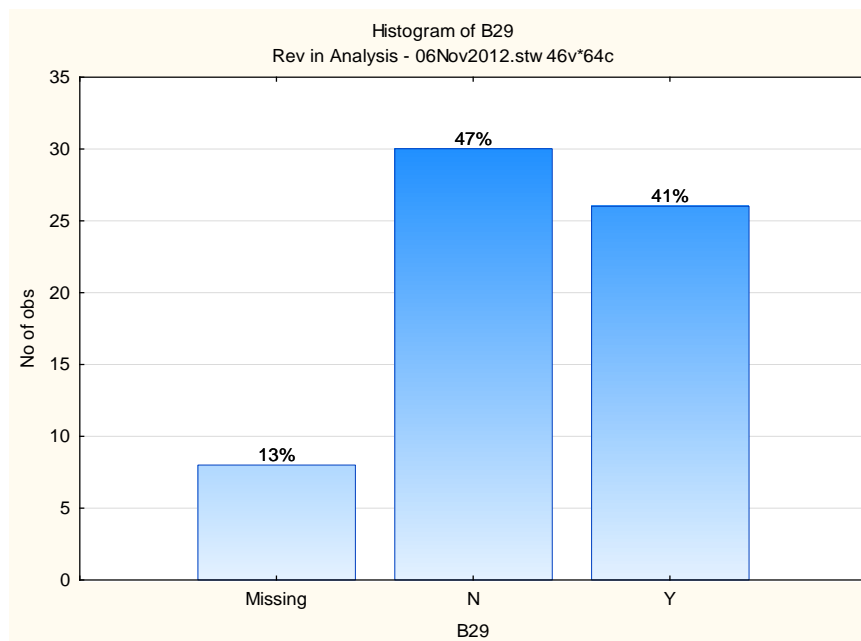
**Table 4.11: Respondents' behavioural responses during the donation process**

Question	Number of respondents	Agree	Disagree	Missing
22. You didn't feel good emotionally during the process	62	48.5%	48.5%	3%
23. You sometimes felt depressed during the process	61	40%	55%	5%
24. You sometimes didn't want to cooperate with the transplant team	62	11%	86%	3%
25. You were scared of dying during the process	62	17%	80%	3%
26. You disliked the procedure more and more	62	34%	63%	3%

It is evident that negative behaviour such as being uncooperative and attitudes such as dislikes were not the intentions by most of the donors in this study.

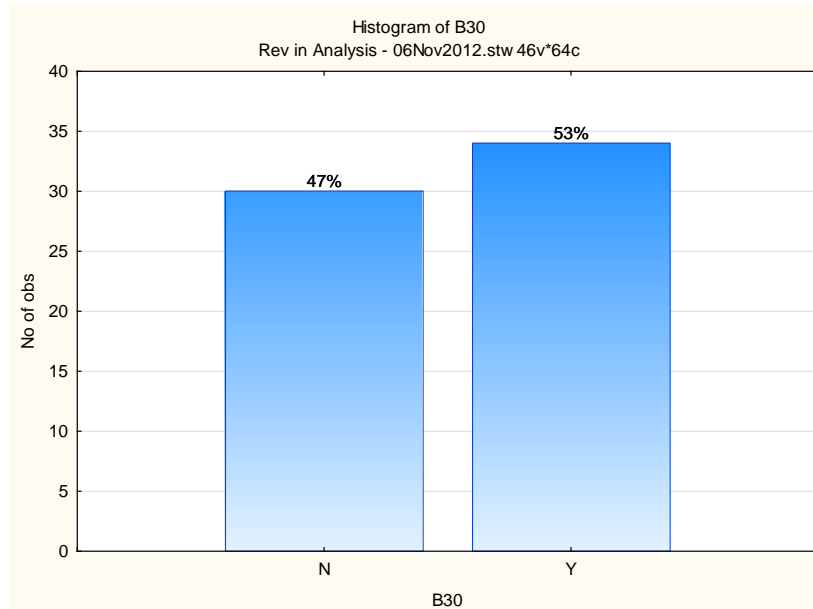
### Subcategory 3: Economics

This sub-section focuses on the financial impact the donation process had on the donor at the time of transplantation.



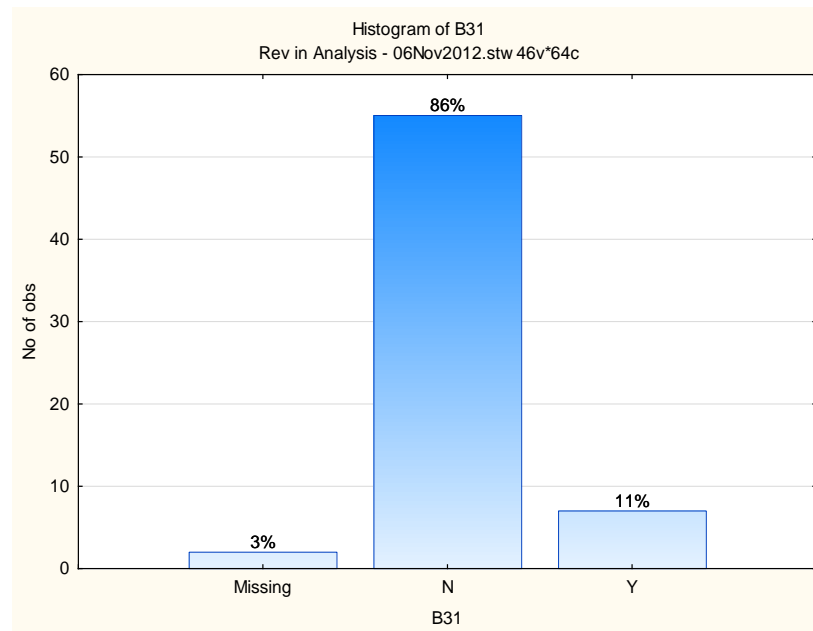
**Figure 4.27: Question 29 - Your sister or brother had a lot of transplant complications**

Data shown in table 4.9 is that the majority of the donors siblings 47% (n=30) did not experience a great deal of transplant complications, a slightly lower number of respondents 41% (n=26) siblings experienced complications and the remainder 12% (n=8) failed to answer this question.



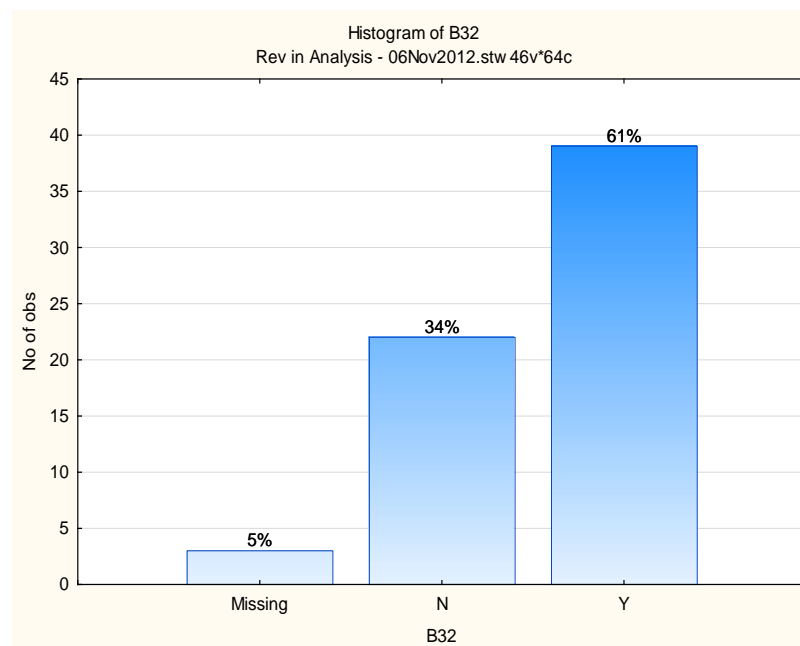
**Figure 4.28: Question 30 - Your sister or brother is alive**

Thirty 47% (n=30) recipients died during or after the transplantation process and a slightly higher number of recipients are still alive 53% (n=34). The high number of recipients that are alive can be an indication that because of fewer transplant complications that were identified by the previous question, more siblings survived.



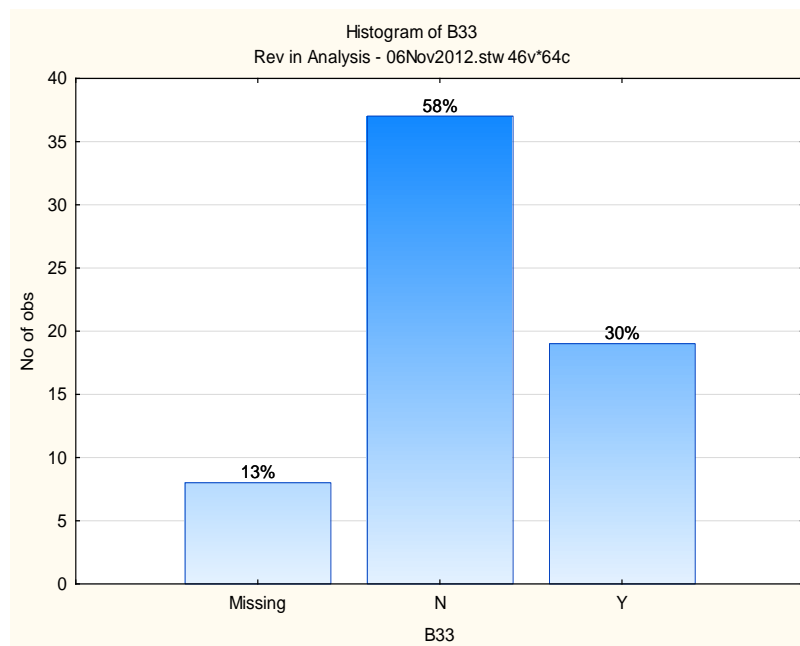
**Figure 4.29: Question 31 - You were a student when the transplant was done**

Most of the respondents 86% (n=55) were not students at the time of transplantation, a few respondents were 11% (n=7) and 3% (n=2) did not provide an answer to the question.



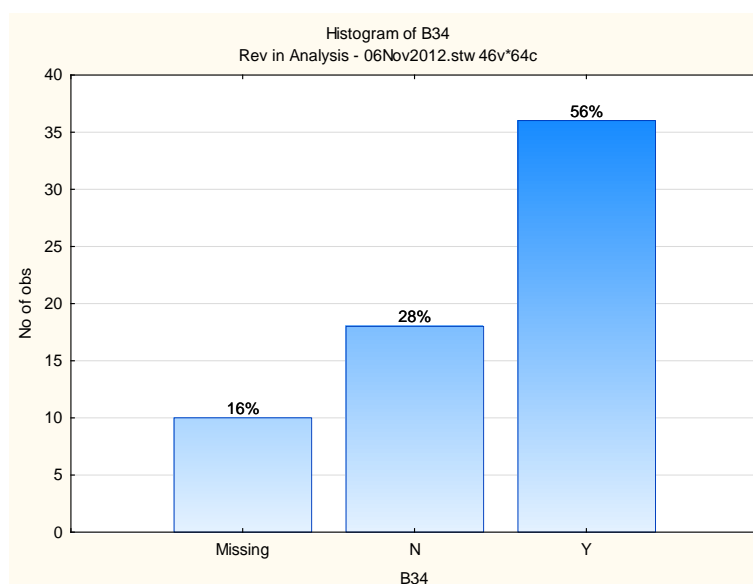
**Figure 4.30: Question 32 - You were employed when the transplant was done**

A substantial number of respondents 34% (n=22) were not employed at the time of the transplant, more than half 61% (n=39) were employed and 5% (n=3) did not provide an answer to the question.



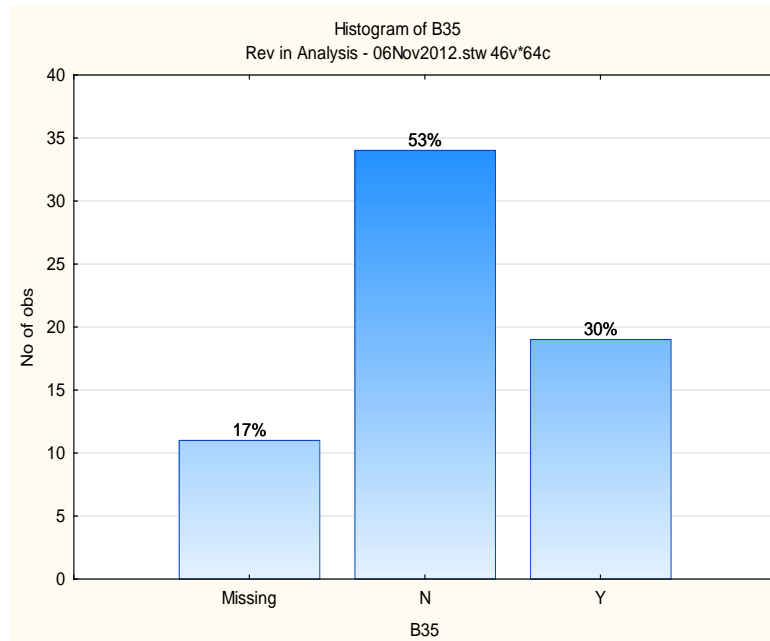
**Figure 4.31: Question 33 - The money that you spent when the transplant process was going on should be paid back to you**

The majority 58% (n=37) of respondents disagreed that the money spent should be paid back, 30% (n=19) of respondents wanted money back and 12% (n=8) had not answered the question.



**Figure 4.32: Question 34 - You should have been given sick leave when you had to go to hospital**

Most of the respondents 56% (n=36) wanted to qualify for sick leave during this time, some respondents 28% (n=18) did not want to be compensated financially by having sick leave during the donation period, whilst 16% (n=10) did not answer the question.



**Figure 4.33: Question 35: You should have been paid when you couldn't earn money while the transplant process was going on**

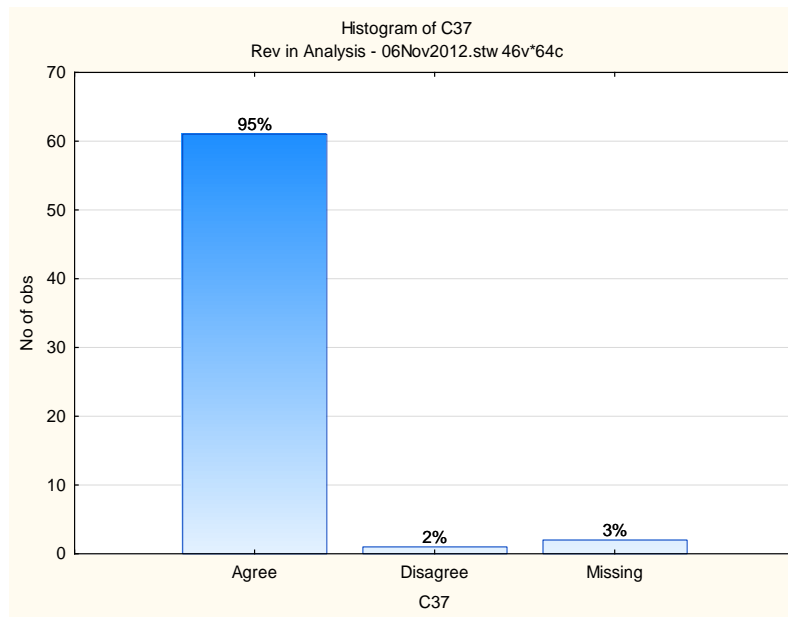
A large number of respondents 53% (n=34) do not want to be compensated financially, where 30% (n=19) wanted to be paid back and there was a relatively high non-response rate 17% (n=11). On the other hand Smith Glasgow and Bello (2007:374) stated that participants were concerned regarding payment for expenses related to medical coverage, compensation for days lost from work for donating bone marrow and care of family members especially children.

**Table 4.12: The financial impact the donation process had on the respondents at the time of transplantation**

Question	Number of respondents	Agree	Disagree	Missing
29. Your sister or brother had a lot of transplant complications	56	41%	47%	12%
30. Your sister or brother is alive	64	53%	47%	0%

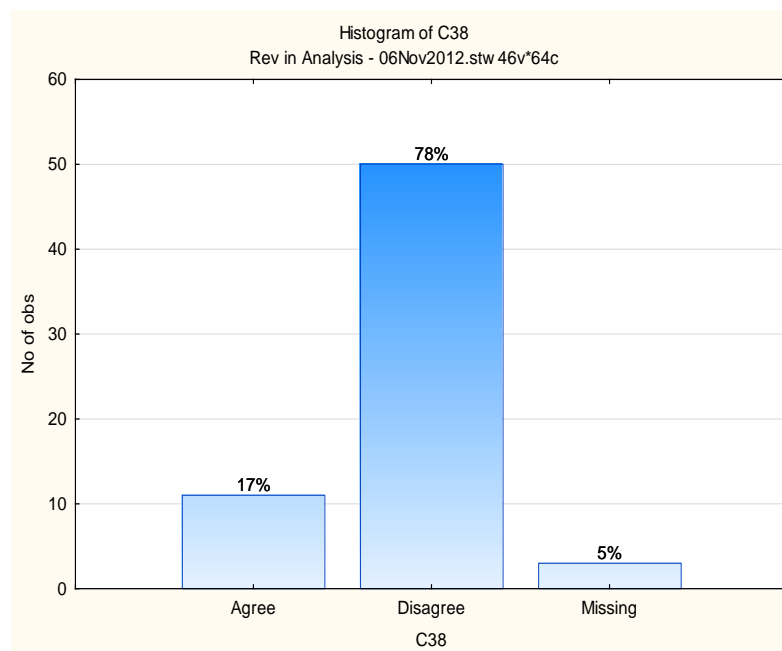
31. You were a student when the transplant was done	62	11%	86%	3%
32. You were employed when the transplant was done	61	61%	34%	5%
33. The money that you spent when the transplant process was going on should be paid back to you	56	30%	58%	12%
34. You should have been given sick leave when you had to go to hospital	54	56%	28%	16%
35. You should have been paid when you couldn't earn money while the transplant process was going on	53	30%	53%	17%

#### 4.4.2.2 Section C: Administration process data



**Figure 4.34: Question 37: You understood why you agreed to donate bone marrow**

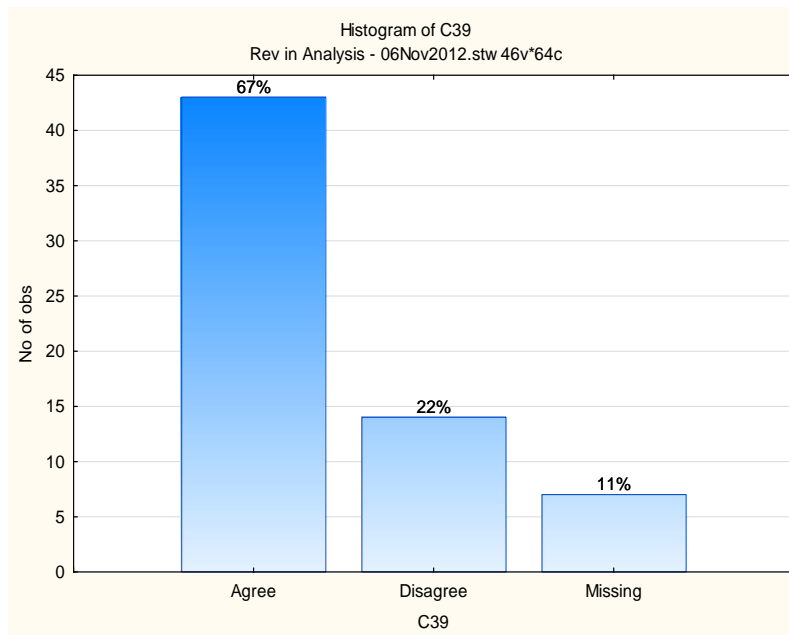
Respondents understanding the process to donate 95% (n=61) featured prominently, 2% (n=1) had no understanding and 3% (n=2) had not answered the question.



**Figure 4.35: Question 38 - You felt that the blood tests went against your right to privacy**

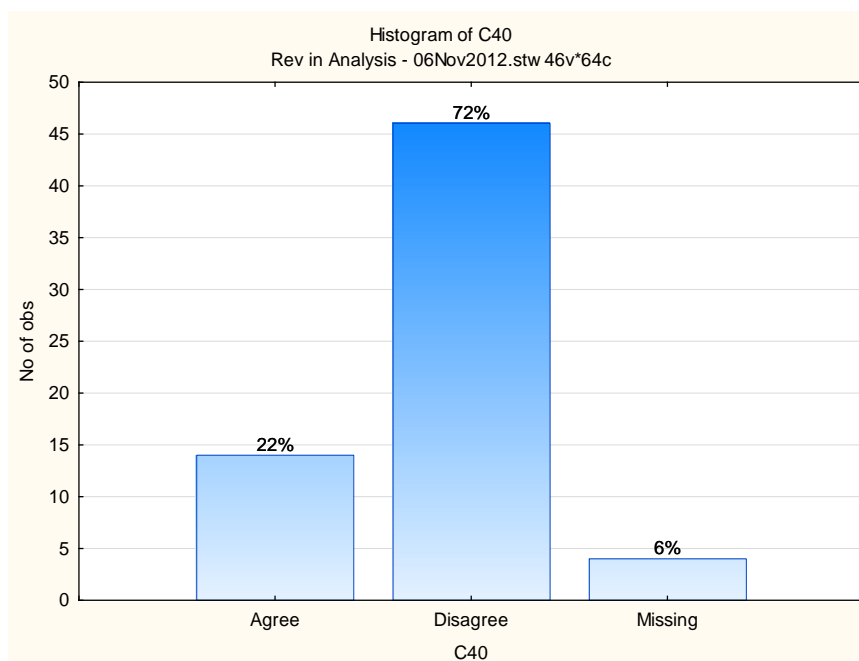
A few respondents 17% (n=11) felt that their privacy was violated, the majority of respondents 78% (n=50) disagreed and 5% (n=3) did not provide an answer to the question.





**Figure 4.36: Question 39 - You felt that the counselling was good**

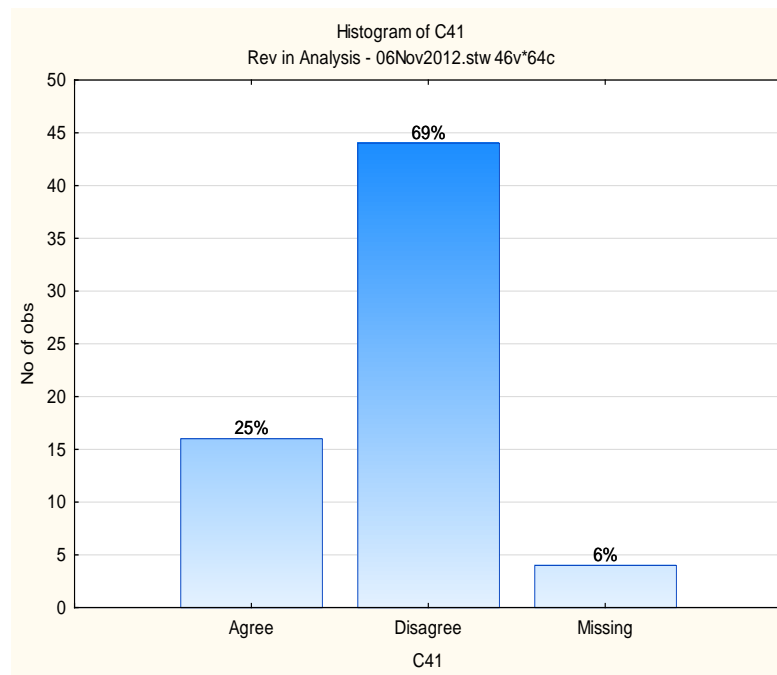
The majority of the respondents 67% (n=43) felt that the counselling they received was good, a substantial number of respondents disagreed 22% (n=14) and 11% (n=7) had not responded to the question.



**Figure 4.37: Question 40 - You were given books, pamphlets and internet information for donors**

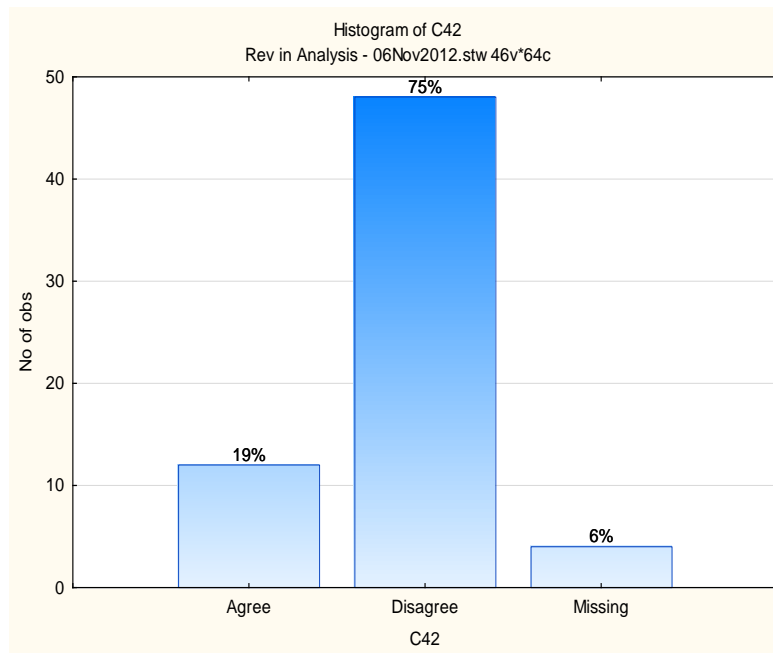
A few of the respondents 22% (n=14) received specific information for donors regarding bone marrow transplantations, whilst the majority 72% (n=46) disagreed and 6% (n=4) had not responded to the question. Williams, Green, Morrison, Watson and Buchanan

(2003:6) identified that information should be provided specifically for sibling donors and recommended that realistic measures of success for each individual sibling pair be given at the initial interview. Moreover, both related and unrelated donors of Haematopoietic Stem Cells (HSC) should be provided with nationally or internationally agreed, well structured information to help them to decide whether donation is feasible (Pamphilon *et al.*, 2009:74).



**Figure 4.38: Question 41 - Hospitals should first try to find a donor from the bone marrow registry before asking a sibling to be a donor**

Some respondents 25% (n=16) felt that the hospital should first seek a donor from the bone marrow registry before asking a sibling; the majority of respondents had not felt that way 69% (n=44) and 6% (n=4) of respondents did not answer the question.



**Figure 4.39: Question 42 - You went for a follow-up appointment after the whole process**

In terms of follow-up visits after the donation process, an overwhelming majority of respondents 75% (n=48) did not go for a follow-up visit postdonation, 19% (n=12) indicated that they went for a follow-up appointment and 6% (n=4) had not provided an answer to the question. Gratwohl and Baldomero (2009:420-423) reported that according to the European Group for Blood and Marrow Transplantation (EBMT) there is no systematic donor follow-up that exists for sibling donors. A postdonation follow-up plan should be clearly arranged with the donor to ensure that alterations in recovery are identified and additional questions are answered (Christopher, 2000:699).

**Table 4.13: Administration process**

Question	Number of respondents	Agree	Disagree	Missing
37. You understood why you agreed to donate bone marrow	62	95%	2%	3%
38. You felt that the blood test went against your right to privacy	61	17%	78%	5%
39. You felt the counselling was good	57	67%	22%	11%
40. You were given books, pamphlets and internet information for donors	60	22%	72%	6%
41. Hospitals should first try to find a donor from the bone marrow registry before asking a sibling to be a donor	60	25%	69%	6%
42. You went for a follow-up appointment after the whole process	60	19%	75%	6%

There was a lack of donor information given to respondents and a lack of postdonation follow-up visits.

#### 4.4.2.3 Statistical significant results

The statistical software package STATISTICA was used to produce the outcome of the demographic variables (employment, education and age at time of transplantation) with section B (psychosocial) that was divided into subcategories (general, behaviour and economics) questions. It was found that psychosocial factors (one in the general and six in the economic category) do influence sibling donors during allogeneic bone marrow transplantation. No differences were found in the other demographic variables identified.

Statistical data analysis was performed to make a probability statement concerning the sibling bone marrow donor population as indicated by Kruger *et al.* (2005:243). The Pearson chi-square test (0.05) was used to test significant differences of all the variables in section B and statistical significances were found for the following variables:

**Table 4.14: Psychosocial data**

<b>Psychosocial data / General information / Emotional</b>	<b>Number of respondents</b>	<b>Statistics / Pearson Chi-square</b>	<b>Df</b>	<b>P</b>
It was difficult for your family when you were away from home / x Education	53	8.705445	df=3	p=.03347

Based on the data provided in table 4.9, a number of observations can be made. The chi-square test indicated a statistical significant relationship between the independent variables education and the influence of the dependent variable (emotional). Descriptive statistics revealed that of the 53 out of the 64 respondents who answered this question (n=16) agreed that it was difficult for their family when they were away from home and (n=34) disagreed. Chi-square results revealed that the majority had low or no education, (n=23) did not complete schooling (other grade) and (n=5) had no schooling which resulted in 53%. Thirteen (n=13) of the respondents who completed this question have a higher education and (n=12) passed grade 12.

**Table 4.15: Economical data**

<b>Psychosocial data / Economics</b>	<b>Number of respondents</b>	<b>Statistics / Pearson Chi-square</b>	<b>Df</b>	<b>p</b>
Your sister or brother had a lot of transplant complications / x Education	50	8.933277	df=3	p=.03019
You were a student when the transplant was done / x Employment	61	42.40594	df=3	p=.00000
You were employed when the transplant was done / x Employment	60	33.08477	df=3	p=.00000
You should have been given sick leave when you had to go to hospital / x Employment	53	10.79307	df=3	p=.01290
You were a student when the transplant was done / x Age Group at Transplant	60	41.95655	df=4	p=.00000
You were employed when the transplant was done / x Age Group at Transplant	59	12.16604	df=4	p=.01616

The variables education, employment and age group at the time of transplantation revealed a significant difference with the respondent's economic situation.

The respondent's economic situation was compared with their educational status. Your sister or brother had a lot of transplant complications / Education: Of the fifty respondents who completed this question the majority (n=23) had other grade educational levels and (n=5) had no schooling. However, (n=12) had a higher education and (n=10) completed grade 12. In this study the high percentage of respondents with a lower level of schooling is significant.

**You were a student when the transplant was done /** Employment and Age group at transplant: of the (n=61) respondents who completed this question (n=40) were employed, (n=16) were unemployed and (n=5) were scholars.

Of the sixty respondents who answered this question the majority (n=34) were within the age group of 30 to 49 years, (n=11) within the age group of 50 to 59, (n=9) within the age group of 18 to 29 years, (n=5) within the age group of 0 to 17 years and (n=1) within the age group of 60 to 65 years. More were employed and in an economically viable age group of 30 to 49 years.

**You were employed when the transplant was done / Employment and Age group at transplant.** Of the (n=60) respondents who completed this question (n=39) were employed, (n=16) were unemployed, and (n=5) were scholars. In the age group category, of the fifty nine (n=32) were within the age group of 30 to 49 years, (n=11) within age group of 50 to 59 years, (n=9) within the age group of 18 to 29 years, (n=5) within the age group of 0 to 17 years and (n=2) within the age group of 60 to 65 years. Being employed at the time of transplant was significantly decreased by donors of age 30 to 49 years.

**You should have been given sick leave when you had to go to hospital / Employment.** Of the fifty three respondents who completed this question (n=37) were employed, (n=11) were unemployed and (n=5) were scholars. The high percentage of respondents that are employed with the request for sick leave was significant.

In short, nearly half of the donors had good education and most of them had some education, 64% (n=41) of the 64 respondents were employed and within the age group of 30–49 years. This can explain why breadwinners who are family orientated in building or maintaining a family life as parents and are in their highest productivity time in their career, need to maintain a clean work record such as a low sick and absent record. The results revealed that financial issues emerged as a relevant factor for many of the stem cell

donors. This indicates that the indirect costs such as time lost from work are particularly important from the donor's perspective.

During Living-donor liver transplantation (LDLT) the medical costs that the patient may be responsible for are those incurred after hospital discharge, including potential late complications of the procedure. Additionally, the right hepatectomy donors can anticipate not returning to work for at least two to three months, which can result in significant income loss depending on the leave policy of the donor's employer (Russo & Brown 2003:S14). This result signifies that donors regarded the bone marrow donation process as a significant financial burden in terms of indirect cost due to time lost from work.

#### **4.5 OPEN-ENDED QUESTIONS**

The four open-ended questions that were asked were analysed using content analysis method as described in chapter three.

Of the 64 related stem cell donors the following numbers of respondents completed the following questions; question 27 (n=63), question 28 (n=62), question 36 (n=57), and question 43 (n=60). This section will focus on the four open-ended questions.

##### **Question 27: You felt that you had to donate your bone marrow (n=63)?**

The majority of the respondents (n=57) expressed that they felt to donate, that it made them feel good that they can save or prolong their sibling's life and to free the sibling from pain and suffering.

##### **Question 28: The death of your sister or brother made you feel like a failure (n=62)**

Majority of the respondents (n=62) indicated that they were not overcome with emotion, guilt and failure despite the outcome of the transplantation process.

##### **Question 36: Did your family lose money because you had to take off from work when the transplant process was going on (n=57)?**

(n=27) respondents indicated no loss of income whilst (n=19) incurred financial loss. (n=8) indicated that they utilised their leave days at work whilst (n=3) respondents indicated their willingness to pay.

##### **Question 43: You felt that you were well prepared for the whole process (n=60).**

Majority of the respondents indicated that they were prepared (n=34) for the process whilst (21) of the respondents felt that there were no recognition for the donor and (n=5) respondents were content and happy to be a donor.

## **4.6 SUMMARY**

This report illustrates the two different forms of analysis of the psychosocial and administrative effects in sibling donors during the haematopoietic stem cell transplantation process. The descriptive statistics were used to assist in arranging numerical data in an orderly and readable manner and to describe single variables. The results of the study were presented and analysed. In this study the economic analysis has shown that allogeneic PBSC transplantation encompasses economic concerns.

The significance is that most donors agreed to donate their bone marrow in order to save a sibling's life. They expressed a deep sense of personal satisfaction for helping their sibling.

## **4.7 CONCLUSION**

In conclusion, the methods of analysis that were used identified factors that correlated with the psychosocial factors that influenced sibling donors during allogeneic bone marrow transplantation. In chapter 5 the findings will be discussed in relation to the literature and appropriate recommendations will be presented based on the findings of the study.



## **CHAPTER 5:**

# **DISCUSSIONS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS**

### **5.1 INTRODUCTION**

The results obtained from the data analysis require interpretation to be meaningful (Burns & Grove 2009:45).

The purpose of this study was to describe the psychosocial factors that influence a sibling donor during allogeneic bone marrow transplantation at a public sector hospital in Cape Town. The study was directed by its objectives, as specified in chapter one, whereby the objectives for the study were to determine

- the psychosocial factors that influence sibling bone marrow donors
- whether the transplant team members explained the administrative process of the transplant in an understandable manner and language
- the effect of the psychosocial factors and administrative process of the allogeneic bone marrow transplantation on the sibling donors.

In this chapter the findings from this study are discussed and conclusions are drawn from the research outcomes. Recommendations are presented that arose from the objectives and recommendations for further studies are made.

Findings from the study provided the researcher an understanding what it is like for the donor whose sister or brother survived or did not survive the stem cell transplantation. The researcher therefore used four open-ended questions and the statistical outcomes were presented in summary tables.

### **5.2 FINDINGS**

Over a period of ten years the stem cell donation process effected the sixty four responding stem cell donors psychologically and socially. The study sample was predominantly Coloured with a mean age of 42 years, at the time of transplant (n=41) were employed and (n=49) of the sixty four respondents had schooling up to higher educational level. These demographic factors of a middle aged group with a financial income and with some education were used to test for statistical differences in the sample for the patients or living donors that were taken care of on a day-to-day basis. Due to live organ donation the health team ought to be more aware of psychosocial factors that will encompass the

person. Despite South Africa's many cultural diversities, blood cell transplantation has not been challenged by the donor's cultural values and beliefs.

Statistical significant results regarding the emotional state and economic situation of the donors were found. As discussed in chapter four, the economic situation of the sibling donor needs to be improved in terms of reducing financial losses for those that are employed, as well as their psychological experiences during and after the donation process.

### **5.2.1 Objective 1**

To determine the psychosocial factors that influence the sibling bone marrow donors

Counselling is a fundamental part of the donation process. The majority of respondents claimed that the counselling process was adequate in helping them in making the decision and developing their personal insight and knowledge into the donation process. As discussed in chapter two, nurses need to be aware of the psychological needs of the client. Hence, counselling the stem cell donor can also function as a valuable enrichment opportunity for the haematology / oncology nurses in their current roles.

This study found that part of the donation process involves invasive procedures that caused the stem cell donor to experience fear. Results of the close-ended questions revealed that the sibling donors developed feelings of anxiety in relation to the invasive procedures such as the bone marrow biopsy and injecting themselves when exposed to these invasive procedures. In addition, they were not only anxious but also experienced inflicted pain caused by these invasive procedures. The study results add further evidence to the literature that demonstrates enhanced psychosocial impact experienced by the donors. Thus, despite the moral obligation the sibling donor has towards his sister or brother the physical pain or discomfort experienced during the donation process outweighed this.

The risk of the donation procedure for the donor (both physical and psychological) is evident because respondents complained of the health problems that they think awaits them during and after the donation process. During a follow-up medical they could express what they felt after the donation period and also get assistance on how to deal with their feelings. However, data of both the close-ended questions and open-ended questions revealed that a postdonation follow-up medical examination for sibling donors in this public sector hospital is lacking.

The rising costs of health care are a growing social concern. Statistical significance regarding the economic situation of the donors was found. In addition, the respondents reported the need for financial support. The donation process of bone marrow and stem cells from related donors at the public sector hospital where the population for this study was taken from are free. However, this hospital is not liable for any medical bills related to the stem cell donation process. Also, some are directly responsible for their own transport and their own accommodation and those who are employed are responsible for leave without pay. Stem cell donors who most likely experience post stem cell donation complications are responsible for their own medical expenses.

### **5.2.2 Objective 2**

To determine whether the transplant team members explained the administration process of the transplant in an understandable manner and language:

Doctors and nurses that are involved in the stem cell donation process should understand the needs of the donors. The researcher was concerned that the donors are not well informed regarding the treatment of the patient. Was there a gap in knowledge from the donors of what the donation process entails? Results of both close-ended questions and open-ended questions revealed that the responding donors claimed that they were well-informed regarding the donation process and understood the treatment plan of the recipient. However, results also revealed that there was a lack in giving visual donor information such as books, pamphlets and internet information. The results concerning the demographics revealed that twenty nine (n=29) respondents had in total no schooling and some respondents had some schooling. This should give the transplant team an indication of bridging the knowledge and information gap between them and the donor in terms of language (a shared lexicon). Because of the country's eleven official languages, language barriers might occur which could result in misunderstandings between the transplant team and the donors which could have a negative psychological effect. Above all, the transplant team should demonstrate the donation process more visually by making use of pictures, written materials in the form of pamphlets and other illustrations to familiarise themselves with the process. The needs for information and education related to stem cell donation has been identified. The plans of care provided by the nurse who seeks to alter the stimuli must fall within the person's ability to cope. Multiple sources of information should be available such as library resources and cancer educational sites on the internet to supplement verbal explanations. Donor evaluation, counselling and obtaining consent were adequately done within the transplant team mainly by doctors and social workers to empower sibling donors regarding stem cell transplantations. For the

nurse practising in the oncology / haematology field it will be invaluable to be part of the formal counselling task provided to these living donors to promote the mechanism of coping during and after the donation process.

### **5.2.3 Objective 3**

The effect of the psychosocial factors and administrative process of the allogeneic bone marrow transplantation on the sibling donors.

Most of the responding donors claimed that they were not psychologically affected by the donation process whereas other respondents reported that they were affected psychologically. It is important that nurses acknowledge the range of intense emotions that living donors are likely to feel so that they can be helped in order to deal with their situation and work through their feelings. This study found that the psychosocial aspects of the procedure were of greater importance than the physical aspects in sibling donors who participated in both successful and unsuccessful HSCT. More information should be directed at the emotional aspects of being a donor. It is important for nurses to assist transplant recipients and donors in dealing with the psychological issues surrounding BMT. Statistical significant results revealed that family members of those donors who had to leave for the donation period were emotionally affected as well. Another important effect of the donation process as stated in objective one is the economic effect it had on the donor. Results revealed that most donors were employed and were concerned about loss due to indirect costs such as time loss from work and loss of income due to leave taken. They also experienced financial losses due to travelling, accommodation, post-donation medical expenses and loss of employment due to hospital attendance. The transplant team must be aware of the fact that the donor is a patient and needs attention.

These objectives were based on the Theoretical framework used by the Roy Adaptation Model which indicated that the person is an adaptive system who has internal processes for coping with change which can be observed through the behaviour of the individual that are manifested through the adaptive modes. Adaptation manifest through the adaptive modes whereby bone marrow donors adapt to treatment and donation of stem cells by adjusting their perceptions of normality to fit the current circumstances or expectations. In addition, being or becoming a stem cell donor which is a live donation is not a physical task but rather a psychological adaptation. The overall contribution of the Roy Adaptation Model is to offer guidance to the nurse to apply this model to nursing practice. This study provided evidence that the physical effect of donating stem cells is not statistical significant. The basis of this whole process is adaptation in terms of how does the healthy person interact with his new environment which is the hospital, the overwhelming task that

is placed on him or her and how this person will cope psychologically during this period and beyond the donation process. For this adaptation process to occur the nurse must place an emphasis on the purpose, the nursing assessment and intervention based on the recipient's outcome.

The focus of knowledge for nursing practice is an understanding of the person as an adaptive system. Hence, according to this model the nurse has a role to promote adaptation. According to the Scope of Practice for the Professional Nurse (SANC) the nurse must provide comprehensive nursing treatment and care for individuals, groups and communities such as the live organ donors. The nurse has to ensure that the donor adapts to pain and anxiety thus to maximise the psychological well-being of the donor. Effective nursing practice in the context of clinically inflicted pain must involve not only technical intervention, but special care in terms of effective nursing interventions that must be given to the person in pain. Results revealed that donors used their coping mechanism which is their religion and spirituality to cope with the donation experience and the complications of the recipient's transplant.

Nurses have to work closely with the medical staff, as well as with relatives to assess the sibling donor's readiness to be physically and emotionally involved in the donation process. This study also revealed that the intentions of the sibling donor to donate their stem cell were favourable. The need to save or prolong their sibling's life, helps the sibling and free the person from pain or suffering that has been determined. More donors felt prepared for the donation process whereas the rest claimed that the donor does not receive enough recognition in terms of information, no counselling, no post-donation medical examination / follow-up and no legal leave benefits were given and financial losses were experienced. However, some felt that they had no choice, but to donate. Also some donors experienced negativity when their siblings experienced complications, as well as graft rejection. When that occurred they responded with shock, blaming themselves and were unable to forgive themselves. Moreover, the stem cell donors expressed a range of feelings, more bad than good. Emotions and stress such as sadness, disappointment, hurtful disgrace, embarrassment and guilt with good ones such as happiness, pleasure and excitement were expressed. In addition, they expressed their willingness to donate their stem cells and willingness to pay their own expenses in order to give the person another chance in life.

In summary, despite the sibling donor's experienced of negative feelings and emotions during and after the donation process they made use of their coping mechanism and support systems to adapt to their situation as identified by the Roy Adaptation Model.

### **5.3 LIMITATIONS OF THE STUDY**

Restrictions and problems in the study were found. The donor participation rate 53% (64/120), was acceptable for mailed questionnaires; however, it might limit the degree to which the findings can be generalised.

The researcher used a quantitative research design with a descriptive approach due to the demographic position of the donors. In addition, the financial impact and time constraints a qualitative research design could have had on the researcher who is the breadwinner of her family and who is full time employed has been taken into account. Also the researcher could have used a few donors who donated recently for reason that the donor's experiences of the donation process as far as ten years ago may not have been adequately captured. The researcher is of the opinion that it would have been preferable if the researcher went the qualitative route in order to get a deeper insight into the participant's feelings and in understanding how the donor experienced the donation process and what it meant for him/her.

Another limitation is that missing data were detected because some respondents failed to complete certain questions. Those respondents were still included in the study to prevent the sample size from becoming reduced and consequently the power of the statistical test is affected.

### **5.4 RECOMMENDATION**

Donors need to get prepared financially by the social worker or financial counsellor to answer questions regarding the out-of-pocket expenses. Research needs to be conducted to determine whether financial support in terms of qualifying for sick leave will ease the effect it has on related living donors in donating bone marrow or stem cells. An organ donation policy needs to be developed and should look at organ donors in terms of a sick leave policy at the workplace to prevent live organ donors from losing valuable working hours that could result in loss of salary. There should also be other financial incentives.

Several other studies found a lack in post-donation follow-up. This study also identified that there is no follow-up system to alleviate and detect post-donation complications. In South Africa there is no established bone marrow registry for siblings and related donors to ensure that there is a post-donation follow-up medical examination. If such a reporting system can be put in place it can capture donor information in terms of recurrence of an adverse event or reaction. This is unlikely for the unrelated donors that have several large

donor registries that are linked to a reporting system of the World Marrow Donor Association (WMDA) that have insight into the occurrence of serious events and adverse effects in relation to stem cell donation (Pamphilon *et al.*, 2009:74).

In a developing country like South Africa donors must get educated in terms of the treatment of haematopoietic stem cell transplantation (HSCT) for leukemia and other haematological diseases. A similar type of study should be replicated with a larger and more diverse sample that includes other Bone Marrow Transplant centres, the public, as well as the private sector to draw patients and sibling donors from different socioeconomic backgrounds compared to the population of the current study.

## **5.5 IMPLICATION FOR NURSING**

Nurses practising in a bone marrow or stem cell transplantation setting are in a prime position to help those living donors to adapt to their new environment and situation. More nursing research in this field can help nurses to understand living donation for transplantation and therefore help to direct nurses as they seek to provide the highest possible quality of care. This can place the nurse at the forefront of good practice in this area.

In addition, further studies need to be undertaken on how nurses experience and deal with the psychosocial factors that influence particularly living donors in a developing country.

## **5.6 CONCLUSION**

The purpose of this study was to determine the psychosocial factors that influence sibling donors during allogeneic transplantation. Based on the findings the haematopoietic stem cell donors coped with the psychosocial impact of the donation process by making use of their coping mechanism to adapt to their situation. However, the motivation to save or prolong their sibling's lives was stronger than the psychosocial impact the donation process had on them. Haematology / oncology nurses are in a position to help minimise the psychosocial impact the sibling or living donors experience during the stem cell donation process.

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## APPENDICES

### ANNEXURE A: STELLENBOSCH UNIVERSITY ETHICS APPROVAL

  
**UNIVERSITEIT • STELLENBOSCH • UNIVERSITY**  
jou kennisvennoot • your knowledge partner

10 June 2011 **MAILED**

Mrs L Mc Kenzie  
Department of Nursing  
2nd Floor  
Teaching Block

Dear Mrs Mc Kenzie

**Psychosocial factors that influence the sibling donors during allogenic bone marrow transplantation.**

**ETHICS REFERENCE NO: N11/02/040**

**RE : APPROVAL**

A panel of the Health Research Ethics Committee reviewed this project on 28 March 2011; the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 10 June 2011 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above-mentioned project number in ALL future correspondence.


Please note that a progress report (obtainable on the website of our Division: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit. Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372  
Institutional Review Board (IRB) Number: IRB0005239  
The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Hélène Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Approval Date: 10 June 2011 Expiry Date: 10 June 2012

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**Fakulteit Gesondheidswetenskappe • Faculty of Health Sciences**

Verbind tot Optimale Gesondheid • Committed to Optimal Health

**Afdeling Navorsingsontwikkeling en -steun • Division of Research Development and Support**

Posbus/PO Box 19063 • Tygerberg 7505 • Suid-Afrika/South Africa  
Tel.: +27 21 938 9075 • Faks/Fax: +27 21 931 3352





## ANNEXURE B: DEPARTMENT OF HEALTH APPROVAL



### DEPARTMENT of HEALTH

Provincial Government of the Western Cape

**REFERENCE:** Lena McKenzie  
**ENQUIRIES:** Dr Bhavna Patel

#### GROOTE SCHUUR HOSPITAL

[bspatel@pgwc.gov.za](mailto:bspatel@pgwc.gov.za)  
Tel.: 021-404-6288 Fax: 021-404-6125  
Private Bag, Observatory, 7935  
[www.capegateway.gov.za](http://www.capegateway.gov.za)

Ms Lena McKenzie  
c/o E5 Haematology Clinic  
New Main Building

E-mail: [Lmckenzie@pgwc.gov.za](mailto:Lmckenzie@pgwc.gov.za)

Dear Ms McKenzie

**RESEARCH:** Psychosocial Factors That Influence The Sibling Donors During Allergeneic Bone Marrow Transplantation

Your recent letter to the hospital refers.

You are hereby granted permission to proceed with your research.

Please note the following:

- a) Your research may not interfere with normal patient care
- b) Hospital staff may not be asked to assist with the research.
- c) No hospital consumables and stationary may be used.
- d) No patient folders may be removed from the premises or be inaccessible.
- e) Please introduce yourself to the person in charge of an area before commencing.

I would like to wish you every success with the project.

Yours sincerely

**DR BHAVNA PATEL**  
**SENIOR MANAGER: MEDICAL SERVICES**  
Date: 15<sup>th</sup> June 2011



**Groote Schuur Hospital**  
Private Bag,  
Observatory, 7935  
Telephone : 021 404-9111

## ANNEXURE C: PARTICIPANT CONSENT FORM

### Participant consent form

#### Dear Participant

You are invited to take part in a research project.

The reason for this research is to find out how you were affected psychologically (emotionally) and socially when you donated bone marrow to your sister or brother. (The process is called allogeneic bone-marrow transplantation.)

Please remember that you don't have to take part in this research if you don't want to!

We will keep all information that you give us confidential - we will not reveal any of your individual information. You will stay anonymous!

If some of the questions that we ask you affect you emotionally we can help you to go for counselling.

This research project has been approved by the Health Research Ethics Committee of Stellenbosch University. The project will be done according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice and the Ethical Guidelines for Research of the Medical Research Council.

#### Declaration by participant

By signing below, I.....  
agree to take part in this research project called *Psychosocial factors that influence sibling donors during allogeneic bone- marrow transplantation*.

Sign in (place).....on (date) .....2011

.....  
**Signature of participant**

.....  
**Signature of witness**



## ANNEXURE D: DEELNEMERTOESTEMMINGSVORM

### Beste deelnemer

Jy word genooi om aan 'n navorsingsprojek deel te neem.

Die rede vir hierdie navorsing is om uit te vind hoe jy sielkundig (emosioneel) geraak is deur die feit dat jy beenmurg vir jou broer of suster geskenk het. (Die proses staan as allogeniese beenmurgoorplanting bekend.)

Onthou asseblief dat jy nie aan hierdie navorsing hoef deel te neem as jy nie wil nie!

Ons sal al die inligting wat jy vir ons gee, vertroulik hou – ons sal niks van jou persoonlike inligting bekend maak nie. Jy sal anoniem bly!

As party van die vrae wat ons stel, jou emosioneel ontstel, kan ons jou help om berading te kry.

Hierdie navorsingsprojek is deur die Universiteit Stellenbosch se Gesondheidsnavorsingsetiekkomitee goedgekeur. Die projek sal uitgevoer word ooreenkomstig die etiese riglyne en beginsels van die internasionale Helsinki-verklaring, die Suid-Afrikaanse riglyne vir goeie kliniese praktyk, en die Mediese Navorsingsraad (MNR) se riglyne vir etiese navorsing.

### Verklaring deur deelnemer

Deur hier onder te teken, stem ek,

....., in om deel te neem aan die navorsingstudie getiteld *Psigososiale faktore wat skenkings tussen broers en susters gedurende allogeniese beenmurgoorplanting beïnvloed*.

Geteken te (plek) ..... op (datum) ..... 2011.

.....  
**Handtekening van deelnemer**

.....  
**Handtekening van getuie**

## **ANNEXURE E: QUESTIONNAIRE**



### **PSYCHOSOCIAL FACTORS THAT INFLUENCE SIBLING DONORS DURING ALLOGENEIC BONE MARROW TRANSPLANTATION**

#### **Survey Questionnaire**

Dear Participant

The reason for this study is to find out how you were affected psychologically (emotionally) and socially when you donated bone marrow to your sister or brother.

There are no right or wrong answers to these questions. What is important is that you tell us honestly how you really felt. That is what will make this study a success.

All your answers will be confidential. We will not reveal any individual information that you give us. Your privacy will be respected and you will remain anonymous – no one will know who you are. But if you would like counselling, you will not remain anonymous, because we will need your personal details (like your name) to give you proper counselling and support.

You are taking part in this study as a volunteer. You can therefore stop taking part at any time. If you do not take part you will not be discriminated against.

This study has been approved by the Health Research Ethics Committee of Stellenbosch University. The study will be done according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice and the Ethical Guidelines for Research of the Medical Research Council. The Ethics Committee can be contacted at 021 938 9075.

If the questions affect you emotionally, our researcher will help you to go for counselling. Our counsellor is Mrs Nomalizo Sineke. Her phone number at work is 021 404 3089 and her cell number is 0728646537. Mrs Sineke is available any time.

You will be able to answer the questions in **30 minutes**.

Most of the questions are “box” questions. All you need to is to put a cross (x) in the box that describes how you felt. The “box” questions have the following headings:

1. Strongly disagree
2. Disagree
3. Mildly disagree
4. Mildly agree
5. Agree
6. Strongly agree

There are also nine “Yes/No question and four “open” questions.

**Example of a “box” question:**

Please put a (X) in the box that describes how you feel about the statement in the left-hand column.

		Strongly disagree	Disagree	Mildly disagree	Mildly Agree	Agree	Strongly agree
	You understood the doctor's explanations				<b>X</b>		

Please give the date on which you fill out this questionnaire:.....

Please return the questionnaire in the pre-paid reply envelope that has been provided.

Thank you for your time and help!

Mrs L Mc Kenzie

Researcher

Tel (w) 021 404 3084

(c) 0839876551

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## SECTION A: Biographical information

Please put a cross (X) in the box that describes you

<b>Gender</b>	Male			Female		
<b>Ethnic group</b>	African	Coloured	Indian	White		
<b>Employment at the time of the transplant</b>	Employed	Unemployed	Self-employed	Scholar		
<b>Educational level at the time of the transplant</b>	Higher education	Grade 12	Other grade	No schooling		
<b>Age group at the time of the transplant (in years)</b>	0-17	18-29	30-49	50-59	60-65	
<b>Age group now (in years)</b>	0-17yrs	18-29yrs	30-49yrs	50-59yrs	60-65yrs	

## SECTION B: Psychological and social information

<b>Subcategory 1: General</b>		Please put a cross (X) in the box that describes how you feel about the statements in the left-hand column					
		<b>Strongly disagree</b>	<b>Disagree</b>	<b>Mildly disagree</b>	<b>Mildly agree</b>	<b>Agree</b>	<b>Strongly agree</b>
1	The doctor explained what was wrong with your sister or brother						
2	You understood the doctor's explanations						
3	You understood why you were going to donate bone marrow						

4	You understood the counsellor's explanations						
5	You were scared of donating part of your body						
6	You were scared of the bone marrow biopsy						
7	You were scared of injecting yourself						
8	You were scared when your groin swelled up because of the leg catheter						
9	You felt pain when the bone marrow biopsy was being done						
10	You felt bone pain because of the injection						
11	You had headaches because of the injection						
12	You couldn't sleep at night						
13	You felt stressed when you stayed in the hospital						
14	In your culture you are allowed to donate part of your body						
15	People avoided you after the whole process						
16	It was difficult for your family when you were away from home						
17	Your family supported you through the whole process						
18	You felt healthy six months after the whole process						

19	Your lifestyle changed because of the whole process						
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	Please put a cross (X) in the box that describes how you feel about the statements in the left-hand column						
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		Yes	No
20	Your lifestyle changed a lot because of the whole process		
21	You felt stressed after the whole process because you couldn't be active immediately		

<b>Subcategory 2: Behaviour</b>	Please put a cross (X) in the box that describes how you feel about the statements in the left-hand column						
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		Strongly disagree	Disagree	Mildly disagree	Mildly agree	Agree	Strongly agree
22	You didn't feel good emotionally during the process						
23	You sometimes felt depressed during the process						
24	You sometimes didn't want to cooperate with the transplant team						
25	You were scared of dying during the process						
26	You disliked the procedure more and more						

27. You felt that you had to donate your bone marrow

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28. The death of your sister or brother made you feel like a failure

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**Subcategory 3:  
Economics**

Please put a cross (X) in the box that describes how you feel about the statements in the left-hand column

		Yes	No
29	Your sister or brother had a lot of transplant complications		
30	Your sister or brother is alive		
31	You were a student when the transplant was done		
32	You were employed when the transplant was done		
33	The money that you spent when the transplant process was going on should be paid back to you		

34	You should have been given sick leave when you had to go to hospital		
35	You should have been paid when you couldn't earn money while the transplant process was going on		

If the statement below describes your situation, tell us more about it

36. Did your family lose money because you had to take off from work when the transplant process was going on

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### ***SECTION C: Administration process***

Please put a cross (X) in the box that describes how you feel about the statements in the left-hand column

		<b>Strongly disagree</b>	<b>Disagree</b>	<b>Mildly disagree</b>	<b>Mildly agree</b>	<b>Agree</b>	<b>Strongly agree</b>
37	You understood why you agreed to donate bone marrow						
38	You felt that the blood tests went against your right to privacy						
39	You felt the counselling was good						
40	You were given books, pamphlets and internet information for donors						



41	Hospitals should first try to find a donor from the bone marrow registry before asking a sibling to be a donor						
42	You went for a follow-up appointment after the whole process						

If the statement below describes how you felt, tell us more about it

43. You felt that you were well prepared for the whole process

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**ANNEXURE F: OPNAMEVRAELYS**  
**PSIGOSOSIALE FAKTORE WAT SKENKINGS TUSSEN BROERS**  
**EN SUSTERS GEDURENDE ALLOGENIESE**  
**BEENMURGOORPLANTING BEÏNVLOED**

**Opnamevraelys**

Beste deelnemer

**Die doel van hierdie studie is om vas te stel** watter psigososiale faktore gedurende allogeniese beenmurgoorplanting ter sprake kom as die skenkers en ontvangers broers of susters is.

**Daar is geen regte of verkeerde antwoorde op hierdie vrae nie; jou inligting is belangrik vir die sukses van die studie.**

**Al die inligting word as vertroulik hanteer, en die navorser onderneem om geen persoonlike inligting wat in hierdie vraelys verskyn bekend te maak nie.** Jou privaatheid, vertroue en anonimiteit sal nie geskend word nie. Sou jy egter berading benodig, sal jou anonimiteit wel aangetas word om te verseker dat jy verdere berading en steun kry.

Jy neem vrywillig aan hierdie studie deel. Jy kan dus op enige tydstip van die studie onttrek, en as jy besluit om nie (verder) deel te neem nie, sal daar nie teen jou gediskrimmineer word nie.

Hierdie studie is deur die Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch goedgekeur, en sal uitgevoer word ooreenkomstig die etiese riglyne en beginsels van die internasionale Helsinki-verklaring, die Suid-Afrikaanse riglyne vir goeie kliniese praktyk, en die Mediese Navorsingsraad (MNR) se etiese riglyne vir navorsing. Die GNEK se telefoonnommer is 021 938 9075.

**As die vrae jou emosioneel ontstel, sal die navorser jou vir berading stuur. Die berader is mev Nomalizo Sineke. Haar kontaknommers is 021 404 3089 (w) en 072 864 6537 (sel), en sy is gedurende sowel as ná kantoorure beskikbaar.**

Dit behoort nie langer as 30 minute te neem om hierdie vraelys van vier bladsye in te vul nie. Al wat jy hoef te doen is om 'n kruisie (x) te maak in die blokkie wat jou reaksie die beste beskryf.

Skryf asseblief die datum in waarop jy hierdie vraelys invul : .....

Dankie vir jou tyd en samewerking om hierdie vrae te beantwoord.

Die reaksieskaal werk soos volg:

1. Verskil ten sterkste
2. Verskil
3. Verskil in 'n mate
4. Stem in 'n mate saam
5. Stem in
6. Stem ten sterkste saam

Daar is ook 'n paar ja/nee-vrae, en vier vrae waarop jy jou eie antwoord moet verskaf.

### Hier is 'n voorbeeld:

Dui aan in watter mate jy met elk van die stellings hier onder saamstem of verskil deur 'n kruisie te maak in die blokkie wat jou die beste pas.

		Verskil ten sterkste	Verskil	Verskil in 'n mate	Stem in 'n mate saam	Stem saam	Stem ten sterkste saam
	Jy het die verduideliking wat die mediese praktisyn gegee het, verstaan.				<b>X</b>		

Beantwoord nou die vrae wat volg. Volg asseblief die instruksies en maak 'n kruisie (X) by die antwoord wat jou die beste pas.

Stuur asseblief die vraelys terug in die ingeslote koevert waarop die posgeld reeds betaal is.

Dankie dat jy ingestem het om aan hierdie opname deel te neem.

Mev L Mc Kenzie

Navorser

Tel: 021 404 3084 (w)

083 987 6551 (sel)

Faks: 021 404 3088 (w)

## AFDELING A: Biografiese inligting

(Maak 'n kruisie (X) in die blokkie wat jou die beste pas, of vul die antwoord in waar nodig.)

<b>Geslag</b>	Manlik			Vroulik	
<b>Etniese groep</b>	Swart	Bruin	Indiër	Wit	
<b>Werksituasie tydens oorplanting</b>	In diens van 'n werkgewer	Werkloos	Eie werkgewer	Student	
<b>Vlak van opvoeding tydens oorplanting</b>	Hoër opvoeding	Graad 12	Ander graad	Geen skoolopleiding nie	
<b>Ouderdomsgroep tydens oorplanting</b>	0–17 jr	18–29 jr	30–49 jr	50–59 jr	60–65 jr
<b>Huidige ouderdomsgroep</b>	0–17 jr	18–29 jr	30–49 jr	50–59 jr	60–65 jr

## AFDELING B: Psigososiaal

<b>Subkategorie 1: Algemeen</b>	Verskaf jou antwoord deur 'n kruisie (X) te maak in die blokkie wat jou die beste pas.						
		Verskil ten sterkste	Verskil	Verskil in 'n mate	Stem in 'n mate saam	Stem saam	Stem ten sterkste saam
1	Die dokter het verduidelik wat jou broer of suster makeer.						
2	Jy het die mediese verduideliking wat die dokter gegee het, verstaan.						
3	Jy het verstaan hoekom jy						

	van jou beenmurg moes skenk.						
4	Jy het die inligting wat die berader jou gegee het, verstaan.						
5	Die gedagte dat jy 'n deel van jou lyf moes skenk, het jou bang gemaak.						
6	Dit het jou bang gemaak dat jy 'n beenmurgbiopsie moes kry.						
7	Dit het jou bang gemaak dat jy jouself moes inspuit.						
8	Die swelling in jou lies wat deur die kateter in jou been veroorsaak is, het jou bang gemaak.						
9	Die beenmurgbiopsie was vir jou pynlik.						
10	Die inspuiting het veroorsaak dat jou gebeente gepyn het.						
11	Die inspuiting het veroorsaak dat jy hoofpyne gekry het.						
12	Jy het gesukkel om snags te slaap.						
13	Jy was baie gestres gedurende jou tyd in die hospitaal.						
14	Dit is in jou kultuur aanvaarbaar om 'n deel van jou lyf te skenk.						

15	Nadat jy van jou beenmurg geskenk het, is jy sosiaal uitgesluit.						
16	Jou familie is negatief geraak deur die feit dat jy van die huis af weg was.						
17	Jou familie het jou deur die hele oorplantingsproses ondersteun.						
18	Ses maande na die beenmurgskenking was jou algemene gesondheid goed.						
19	Die beenmurgskenking het jou leefstyl beïnvloed.						

	Maak 'n kruisie (X) in die blokkie wat jou die beste pas.		
		<b>Ja</b>	<b>Nee</b>
20	Die feit dat jy 'n skenker geword het, het jou leefstyl aansienlik beïnvloed.		
21	Die feit dat jy onmiddellik na die beenmurgskenking onaktief was, het jou stresvlak opgejaag.		

<b>Subkategorie 2: Gedrags-aspekte</b>		Verskaf jou antwoord deur 'n kruisie (X) te maak in die blokkie wat jou die beste pas.					
		Verskil ten sterkste	Verskil	Verskil in 'n mate	Stem in 'n mate saam	Stem saam	Stem ten sterkste saam
22	Jy het emosioneel ontstel gevoel terwyl die proses van die beenmurgoorplanting aan die gang was.						
23	Jy het by tye depressief gevoel terwyl die proses van die beenmurgoorplanting aan die gang was.						
24	Jy het partykeer geweier om saam te werk met die span wat die beenmurgoorplanting gedoen het.						
25	Jy was bang jy sterf gedurende die beenmurgskenking.						
26	Jy het ervaar dat jy die mediese prosedures al minder kon verduur.						

27. Jy het gevoel jy is emosioneel verplig om van jou beenmurg te skenk.

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28. Toe jou broer of suster oorlede is, het dit jou laat voel jy is 'n mislukking.

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<b>Subkategorie 3: Ekonomiese fasette</b>		Maak 'n kruisie (X) in die blokkie wat jou die beste pas.	
		<b>Ja</b>	<b>Nee</b>
29	Jou broer of suster het komplikasies weens die oorplanting ervaar.		
30	Jou broer of suster het dit oorleef.		
31	Jy was 'n student toe die beenmurgoorplanting gedoen is.		
32	Jy het 'n werk gehad toe die		



	beenmurgoorplanting gedoen is.		
33	Jy behoort vergoed te word vir jou uitgawes gedurende die tydperk toe die oorplanting gedoen is.		
34	Jy behoort siekverlof te kan kry om afsprake by die hospitaal na te kom.		
35	Jy behoort vergoed te word vir jou verlies aan inkomste gedurende die tydperk toe die oorplanting gedoen is.		

36. Het jou familie finansiële skade gely weens die werktyd wat jy verloor het gedurende die tydperk toe die beenmurgoorplanting gedoen is?

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### **AFDELING C: Administratiewe proses**

(Verskaf jou antwoord deur 'n kruisie (X) te maak in die blokkie wat jou die beste pas.)

		Verskil ten sterkste	Verskil	Verskil in 'n mate	Stem in 'n mate saam	Stem saam	Stem ten sterkste saam
37	Jy het verstaan waarvoor jy toestemming gee.						
38	Dit het jou reg op privaatheid geskend dat jy moes bloedtoetse ondergaan.						
39	Die berading wat jy gekry het, was goed genoeg.						

40	Jy het geskrewe inligting vir skenkers ontvang wat uit boeke en pamflette en vanaf die internet geneem is.						
41	Die hospitaal moet 'n bruikbare skenker uit die beenmurgregister soek voordat hulle 'n broer of suster mag vra.						
42	Daar is 'n opvolgbesoek vir jou gereël nadat die beenmurgoorplanting gedoen is.						

43. Is jy goed genoeg op die beenmurgskenking voorberei?

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## ANNEXURE G: APPLICATION FOR FINANCIAL ASSISTANCE

### Application for financial assistance

I am currently busy with my Masters degree in Nursing at Stellenbosch University and I am in the final stage of writing the research findings and I am applying for financial assistance at the Groote Schuur Hospital Region Nurses Education Trust (RNET) and Haematology Research Fund.

The reason for doing this course is to understand the world of nursing research and therefore will be able to provide evidence-based care to my patients. The research is also needed and necessary to place me in a more competent teaching and mentorship role. The funding needed is to conduct the research such as paper and printing cost, translation and editing of questionnaire, postage, editing of thesis and telephone calls.

**Funds paid to date:** Edit and translation of Questionnaire R1214.96

Postage R2687.60

The study findings will be presented to the nursing research committee of Groote Schuur Hospital, other nursing committees and for possible submission for publication in a clinical journal such as Psycho oncology or Haematologica.

ITEM	UNIT/EACH	QUANTITY	TOTAL
Questionnaire translation and edit	0.60		R1214.96
Paper	0.80	2000	R160.00
Envelopes, stamps and postage stampsPostage			R2687.60
Editing of thesis	7 000	1	R7000.00
Printing	0.80	600	R480.00
Telephone	0.57/UNIT	200	R114.00
Cellular calls	2.50 / min	200	R500.00
ESTIMATED TOTAL			R12156.56

## ANNEXURE H: DECLARATION BY LANGUAGE PRACTITIONER



3 Beroma Crescent  
Beroma  
Bellville 7530

### *TO WHOM IT MAY CONCERN*

This letter serves to confirm that the undersigned

**ILLONA ALTHAEA MEYER**

has proof-read and edited the document contained herein for language correctness.

(Ms IA Meyer)

SIGNED



TAALSENTRUM  
LANGUAGE CENTRE  
IZIKO LEELWIMI



UNIVERSITEIT  
STELLENBOSCH  
UNIVERSITY

15 February 2013

Ms L McKenzie  
76 10<sup>th</sup> Avenue  
Kensington  
Maitland  
7405

Dear Ms McKenzie

The Stellenbosch University Language Centre hereby confirms that the English documents listed below had been edited; the changes to the edited texts had been done using MS Word's tracked changes function. Thereafter the edited English texts had been translated into Afrikaans:

*Research questionnaire*

*Participant Consent Form*

Please contact me if you have any questions.

Regards

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**Alta van Rensburg**

**Head: Language Service**

**Stellenbosch University Language Centre**

**Tel: 021 808 2231**

**Fax: 021 808 2863**

**E-mail: [avrens@sun.ac.za](mailto:avrens@sun.ac.za)**



To whom it may concern

This letter serves as confirmation that I, Lize Vorster, have performed the technical formatting of Lena Mc Kenzie's thesis which entails ensuring its compliance with the Stellenbosch University's technical requirements.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Lize Vorster', is written over a large, light blue 'X' mark.

Lize Vorster